DOCUMENT RESUME

ED 413 683 EC 305 940

AUTHOR	Fry, Ronald R., Ed.
TITLE	Shaping State Rehabilitation Programs through Consumer Partnerships: Issues and Strategies. Report from the Study Group.
INSTITUTION	Wisconsin Univ.-Stout, Menomonie. Stout Vocational Rehabilitation Inst.
SPONS AGENCY	National Inst. on Disability and Rehabilitation Research (ED/OSERS), Washington, DC.
PUB DATE	1996-03-00
NOTE	111p.; University of Wisconsin-Stout Research and Training Center Institute on Rehabilitation Issues (22nd, New Orleans, LA, March 1996).
CONTRACT	H133B80049-90
PUB TYPE	Guides - Non-Classroom (055)
EDRS PRICE	MF01/PC05 Plus Postage.
DESCRIPTORS	Adults; Advisory Committees; Change Strategies; Cooperation; Cooperative Programs; *Disabilities; Leadership; Participation; Program Improvement; *Rehabilitation Programs; *Self Advocacy; *Self Determination; *State Agencies; *Vocational Rehabilitation

ABSTRACT

Targeted to state vocational rehabilitation administrators and leaders, this document discusses the recommendations of a study group that investigated approaches, ways, methods, and strategies for increasing the involvement of individuals with disabilities in the operation and management of state agency rehabilitation programs. Part 1, "Consumer Involvement: Basics and Background," addresses the vision and values that must be embraced to ensure consumer involvement in rehabilitation programs, including open communication, trust and respect, leadership development of individuals with disabilities, continuous striving for improvement, and diversity. The evolution of consumer involvement in vocational rehabilitation is described. Part 2, "Consumer Involvement: How to Make it Happen," begins by discussing top-down endorsement strategies. Involvement via statewide councils is also addressed and includes a discussion of the makeup, roles, and responsibilities of state rehabilitation advisory councils. Recommendations are made for council support strategies, recruitment strategies, and operation strategies to ensure greater consumer involvement. The final section discusses strategies for consumer agency partnerships related to legislative advocacy and networking strategies, personal development strategies, and state and/or local planning, policy development, and evaluation strategies. Part 3 provides sample program statements and plans for consumer involvement, organizational resources, and relevant articles. (Contains 15 references.) (CR)

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TWENTY-SECOND INSTITUTE ON REHABILITATION ISSUES

Shaping State Rehabilitation Programs Through Consumer Partnerships: Issues and Strategies

March, 1996

Institute on Rehabilitation Issues
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Report from the Study Group on

Shaping State Rehabilitation Programs Through Consumer Partnerships:

Issues and Strategies

Twenty-Second Institute on Rehabilitation Issues
New Orleans, Louisiana
March, 1996

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The contents of this IRI document were developed under a grant (H133B80049-90) from the National Institute on Disability and Rehabilitation Research of the Department of Education and the Rehabilitation Services Administration. However, these contents do not necessarily represent the policy of those agencies, and you should not assume endorsement by the Federal Government

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Foreword

During 1994-1995, a Prime Study Group sponsored by the Research and Training Center at the University of Wisconsin-Stout studied the topic of consumer decision making and choice in the vocational rehabilitation process. That study group focused specifically on approaches, ways, methods, and strategies for creating a true partnership between the vocational rehabilitation consumer and the vocational rehabilitation professional, a partnership in which the consumer would have an equal voice in the planning and direction of his/her individual rehabilitation program and process. The outcome of the work of that Prime Study Group was the document titled *Operationalizing Consumer Decision Making and Choice in the VR Process* (Fry, 1995).

In 1995-1996, another Prime Study Group produced this document which focused its thinking toward approaches, ways, methods, and strategies for increasing the involvement of individuals with disabilities in the operation and management of a state agency rehabilitation program. The main question was "in what ways can people with disabilities (whom the state programs are designed to serve) have a greater voice in the philosophy, management and supervision of that program?" To that extent, this document's study group looked at organizational barriers, practices, and attitudes that have prevented or limited the input of ideas, points-of-view, and advice from people with disabilities.

There were many similarities in the discussions that took place in both study groups. Both looked hard at and identified "old" attitudes and ways of doing things and both generated (or recognized) "new" attitudes and ways of thinking. However, their charges were different and their recommendations, contained in their individual study group documents, pointed at providing solutions to different problems and concerns.

It is the wish of this Prime Study Group that the content of this document will help vocational rehabilitation administrators, managers, and supervisors recognize the need to involve people with disabilities in significant ways in the management and operation of their state vocational rehabilitation programs. The group also acknowledges the fact that this document does not contain "all the answers" and to that extent, we invite your comments and contributions.

Acknowledgments

Many people were involved along the way in the development and publication of this IRI study. The description of the IRI process that follows should help the reader to understand the many ways people are involved in the IRI and, therefore, the reasons I owe them gratitude.

A first step in the process is the development of topics for the IRI Prime Study Group to study. We acknowledge the efforts of the Council of State Administrators of Vocational Rehabilitation (CSAVR), the National Institute on Disability Related Research (NIDRR), the Rehabilitation Services Administration (RSA), and the many state vocational rehabilitation agency administrators who submitted topics for study consideration.

Following the development of the topic list, the IRI Executive Committee met, discussed, and agreed on three topics for final study. Theirs was a difficult task because all the topics deserved study. We acknowledge and appreciate that committee's work.

We wish to thank the state vocational rehabilitation agency administrators who nominated individuals to serve on this Prime Study Group. Serving on a study group is a considerable commitment in time and effort and we appreciate the fact that state administrators allowed their employees time to participate in this group.

Most importantly, we thank the members of the Prime Study Group (see page iii). These are the real authors who did the thinking, critiquing, writing, (and rewriting) of 100 percent of the body of this document. This publication represents their hard work, which included three meetings of several days each and involved many hours in between those meetings to complete writing assignments.

We acknowledge the work of the Full Study Group (listed on page iv). These individuals took the time to read, discuss, and critique this document. Their feedback was invaluable for further improving the quality of this document.

This editor wishes to personally thank two individuals who, in addition to serving on the Prime Study Group Committee, also agreed to assist me on the Editorial Committee, the last step in finalizing the content of the document. Ms. Molly Holsapple of the Oregon Department of Human Resources and Nancy Long, University of Northern Illinois, helped me greatly in putting the "finishing touches" on the document.

Finally, Jean Davis of our Research and Training Center staff composed this document. The attractive appearance of the document you are about to read speaks for itself.

Ronald Fry
IRI Study Group Coordinator and Editor

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Part I

Consumer Involvement

Basics and Backgrounds

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Introduction and Rationale

This IRI document offers great opportunity for state vocational rehabilitation programs and people with disabilities to work cooperatively as partners to develop programs that will affect not only the rehabilitation process but people with disabilities and rehabilitation professionals as well. The primary target audience for this work is state vocational rehabilitation administrators and leaders. Consumer groups will find valuable information as well, and they are encouraged to adapt and to adopt this information in their work with state agencies. The charge to readers is to view openly and honestly their beliefs, values, and knowledge about vocational rehabilitation (VR); to confront their biases and fears; and to take positive action.

Consistent with the content and intent of Title I, Section 105 of the Rehabilitation Act (1992 Amendments), *consumer involvement* in the shaping of state programs refers to the *active, equal*, and *meaningful* participation of persons with disabilities, their family members, and advocates as partners with the state agency. Their role in shaping state programs is to work as part of a team to develop, establish, implement, monitor, and evaluate the policies, programs, and services provided by the state rehabilitation agencies. For the purposes of this discussion, the term state vocational rehabilitation agency includes both general vocational rehabilitation and state agencies for the blind.

We, the members of the Prime Study Group, will present to you ideas and guidelines for effective strategies that you may use to create opportunities to strengthen your state vocational rehabilitation agencies. This strengthening will be accomplished through positive and effective full-partnerships with people from the disability community. We believe that as the partnerships grow and prosper, so will rehabilitation outcomes, potential funding sources, and participants' feelings of effectiveness. The 1992 Amendments to the Rehabilitation Act supports this and calls for "full inclusion and integration into society, employment, independent living, family support, economics, and social self-sufficiency of individuals with disabilities" (Botterbusch & Menz, 1993, p. 1). We need to be open to all sources of input to this process, especially families of persons and self-advocates with the most severe disabilities.

It is important to note that the scope and focus of this document is on consumer involvement at the programmatic, not individual, level. We recognize the need for consumers to participate as partners in choices relating to their own rehabilitation plans and services, and we support that need. However, for this document, consumer involvement at the individual level is considered a natural predecessor to the larger state program level involvement. As such, little attention will be given here to the role of consumers in deciding their own futures. Rather, greater attention is given to the need for many different people with disabilities to influence the development of broader programmatic concerns. For more information on the individual level of involvement, interested readers are referred to two previous IRI documents *Client Involvement: Partnerships in the Vocational Rehabilitation Process* (Corthell, 1988) and *Operationalizing Consumer Decision-Making and Choice in the Vocational Rehabilitation Process* (Fry, 1995).

Why should you care about this topic? Why should you embark on a plan to enhance consumer involvement to reflect a meaningful and true partnership? There are several ways to answer these questions. Federal mandates established over the years relative to consumer representation on state advisory councils were strengthened with the passage of the 1992 Amendments to the Rehabilitation Act. In addition, strong programs such as the Independent Living Services Program would not have been developed without the input and guidance of the consumer groups. Perhaps a more compelling reason can be found in the sheer pragmatics of the situation: these partnerships assure that the agency offerings are customer-driven and relevant to the target populations being served.

This is not a new or unique idea. It has been used in the world of marketing for decades. Businesses, when they contemplate offering new products (or modifying old ones), frequently conduct surveys of targeted focus groups. Gauging from the responses of focus group members, they design, adapt, or develop products or advertising strategies that have potential for success. Businesses do not do this because it is morally or ethically correct. They do it to assure that their product will succeed and will continue to exist, if not thrive. State vocational rehabilitation agencies have a similar need. Their products are services and programs for individuals with disabilities. Altruistically speaking, there is a moral and ethical component of the delivery of vocational rehabilitation services. There is also a legal component as mandated in the Rehabilitation Act and federal regulations, as well as a business survival component. The most compelling reason is that involved consumers are well-informed consumers. Well-informed consumers will serve state program administrators well in assisting to make tough decisions relative to funding.

All of these factors create a demand for meaningful involvement of consumers as partners in the development, planning, implementation, review, streamlining, and retooling of service and programs provided through state agencies. With 1997 Amendments looming in the very near future, the implementation of full partnership is paramount. *With strong, healthy coalitions between vocational rehabilitation and the disability community, great opportunity can be seized out of this situation.*

To provide you with a practical document on the topic of consumer involvement, we will present an introduction and rationale for why this approach to shaping state programs is not only viable but critical for continued success. We will present you with the *vision and values* that must be embraced to assure the success of this effort. In addition, you will learn about the natural evolution of *consumer involvement in rehabilitation* that laid the groundwork for this discussion. You will be presented with recommended strategies for ways to implement consumer involvement in advisory councils as mandated by the Rehabilitation Act (1992 Amendments). Moreover, you will be supplied with *ideas for involvement* that reach far beyond roles on councils. In providing you with this information, we have strived to present both a practitioner's perspective and a consumer's perspective. As a group preparing this document we held strongly to the belief that diversity issues should be recognized and addressed. While not the priority focus of this work, these issues were addressed as they relate to persons with disabilities from racial and ethnic minority groups as well as persons with disabilities who are often underrepresented in consumer advisory effort.

Finally, in this document you will be provided with a variety of materials in the resource section that you may wish to access as you work to enhance your agency's meaningful involvement of persons with disabilities and their families and advocates in efforts to develop, implement, evaluate, and monitor state vocational rehabilitation programs.

We need to construct a safety net to allow for the normal starts and slips that can occur. There will be people who cannot make the transition to partnership. There will be casualties and losses and some people will want to leave. In order to reduce these casualties, it is important for all partners to understand and share common visions and values. The vision and values held by the partners must be consistent with the goal of full and equal partnership of consumers in shaping state vocational rehabilitation programs. The vision and values identified by the Prime Study Group critical for the partnerships we envision are detailed in the following section.

Vision and Values

A vision is to see, to perceive, and to have foresight. It can be a thought, a feeling, or even a program that is powered by a drive to make it come true. A vision evolves from values which are the spirit that makes the goal come true. A system cannot survive without a vision or goal and, while at times the vision may be dimmed, it does not mean it has vanished. A common vision and set of values shared by all partners, persons with disabilities, and the vocational rehabilitation are essential for the success of consumer involvement in shaping state rehabilitation programs.

Vision:	Consumers and rehabilitation agency staff working to shape state rehabilitation policy, program development, evaluation, and monitoring.
Values:	Open communication Trust and respect Leadership Continuous striving for improvement Diversity

The spirit that drives people toward achieving a vision are the values that shape it. The values necessary to foster consumer involvement in shaping state rehabilitation include (a) open communication between partners, (b) trust and respect for each other and the process, (c) development and honing of the leadership skills of both rehabilitation personnel and consumers, (d) a continuous striving by all partners for improvement of themselves as people and of the rehabilitation system as a whole, and (e) a welcoming of the diversity that comes when people with disabilities and their families and advocates, especially those who are also from racial or ethnic minority backgrounds, work closely together.

Open Communication

Perhaps the most basic value held by the Prime Study Group is that of open communication. Open communication is essential and extremely valuable to this partnership. It allows for inclusion. When people share with others, they invite them into their world. The ability to convey ideas in a straightforward manner with people who are able to respect differences is crucial to the success of consumer involvement. Good listening skills are a must for all partners involved in the process of setting policy, making program decisions, and evaluating and monitoring successes of the rehabilitation program. Each partner must listen to what the other person is saying and learn what experiences have influenced them. Listening requires a personal courage and the need to be open and sensitive, especially when there are differences. Along with good listening, communication among partners in consumer involvement requires negotiating skills. Negotiating is an art. It uses many skills to bring about the desired results: primary among them is the ability to compromise—to give up something that may be important to one person in exchange for something that is important to another. The development of good listening skills and an environment that fosters open communication are essential to this process.

Trust and Respect

Open communication is closely related to high levels of trust and respect. Trust in each other's motives and goals is a clear result of open communication between partners. Respect for each other and for different backgrounds, experiences, and perspectives brought to the discussion allows trust to be forthcoming. For example, it is important to understand that persons with disabilities frequently see themselves as living in a culture within which self-advocacy and independence are highly respected goals. It is equally important to respect the commitment and experience of many vocational rehabilitation and independent living professionals. Trust in both the process and the principle that the end result will be one that represents the best interests of all involved is another characteristic of a successful consumer program.

Leadership

For persons with disabilities to be partners in the shaping of state rehabilitation programs, it is imperative that they develop leadership skills, management skills, and decision-making skills. They are advancing in the arena of self-determination and leadership skills are needed to ensure success. Opportunities for the development of leadership skills must be provided to facilitate the development of these skills in consumers who will serve as partners in the shaping of state programs.

It should be noted as well that effective leadership skills in state agency staff are also a highly desired characteristic. State agency personnel should work to develop an ability to lead.

Continuous Striving for Improvement

All of the values mentioned so far are not static. They incorporate ideas that are always evolving and that require life-long learning and striving for achievement. The ability to lead is something at which most of us must work. For a partnership to succeed, the rehabilitation system should foster the concept that all partners are people who develop successful decision-making skills. They mutually decide on a plan of action to achieve their goal, and they pursue it. It is recognized that consumers may begin to practice these skills within their individual written rehabilitation or employment plans. These skills will serve as the building blocks for participation in the larger program concerns that are addressed in shaping state rehabilitation programs.

Some examples of continuous quality improvement training activities targeted at consumers, council members, and vocational rehabilitation staff may include:

- Developing team work and consensus building skills
- Developing of decision-making skills, i.e., the ability to obtain, synthesize and, analyze information; the ability to anticipate consequences (positive and negative) of possible decisions
- Developing of leadership skills

Diversity

Persons with disabilities and vocational rehabilitation staff will have similarities and differences that will be influenced by their own personal values, their family values, and their individual needs. Respecting this diversity will lead to a respect for each individual and will make a stronger basis for the partnership. Vocational rehabilitation agencies must first examine, with 20/20 vision, their own history of service to diverse populations. They must continuously strive to eliminate barriers that are a result of cultural biases. Commitment to effectively serve each state's diverse population of persons with disabilities will, at the pragmatic level, influence strategic planning and program development goals. It will also affect personnel development in a way that assures hiring, training, retention, and advancement of qualified staff to serve consumers from culturally diverse backgrounds.

The Evolution of Consumer Involvement: Past, Present, and the Future

Prime Study Group members believe that vocational rehabilitation in the past established the foundation for the consumer activism that is now growing and changing. We believe that an understanding of this history will help all readers find and shape their roles in the future in line with the vision and values identified. The vocational rehabilitation process has paved and will continue to pave the way for people with disabilities to become knowledgeable and empowered and to develop the leadership/self-advocacy skills that influence and guide the delivery of rehabilitation services. This section will therefore examine major trends in rehabilitation related to legislation, consumer access, service delivery, and consumer empowerment. Information will be presented and then summarized in Table 1. Using the 1992 Amendments as a benchmark, this section will review the evolution of consumer involvement in the past (1960-92), and present (1992-1996), and the future.

1960s-1970s: A Period of Growth and Expansion

During the 1960s and 1970s vocational rehabilitation programs experienced a period of unprecedented growth and expansion. Ample federal funding, a strong labor market, and new consumer groups identified in the Rehabilitation Act of 1973 encouraged expansion in staffing and programming. Moving beyond physical restoration of war veterans, programs and services began to be developed to serve students in transition from school to work, the socially disadvantaged, and specific disability groups (e.g., persons with mental disabilities, African-Americans with disabilities).

This initial program expansion grew out of a strong political and economic environment and growing professional movement rather than a ground swell of consumer demand. Services generally were developed based upon a "medical model" focusing upon a person's disability and limitations. Professionals communicated a "we know what is best for people with disabilities" philosophy. Vocational rehabilitation agencies often used a standardized production model providing a cookie cutter "one size fits all" approach to maximize the number of persons served. Within this environment clients getting vocational rehabilitation services were most often appreciative and did not question the expertise of a rehabilitation counselor.

The 1970s was the period in which the independent living movement was born. Vocational rehabilitation was influenced by at least five broad social movements active during the decade: civil rights, consumerism, self-help, demedicalization, and deinstitutionalization (DeJong, 1979; Nosek, 1992). From the civil rights movement came an awareness of the impact of exclusion based on personal traits and the individual's right to a place in society's mainstream. From consumerism was drawn each person's responsibility to assess and communicate their own needs, as well as evaluate and control services they received. From the 1960s came individuals who were demonstrating their independence, acting as peer counselors, advocating for others to have opportunities to live and work outside nursing homes or other institutions, and providing a challenge to the medical model dominated by professionals. All of these movements meant that the 1970s was a decade of increased visibility, opportunity, and consumer expectations for vocational rehabilitation.

Table 1. Vocational Rehabilitation and the Consumer: Past, Present, and Future

	Past (1960-1992)	Present (1992-1996)	Future (1997 & Beyond)
Legislation	Pre-1973 mandate rehabilitation services to disabled veterans. Primary service is physical restoration. 1973 Title VII Independent Living included identification of services to persons with mental disabilities and others.	Legislation mandates rehabilitation services for people with disabilities with emphasis on employment outcomes. Legislation calls for choice and full partnership in the designing of services.	Consumers of rehabilitation services provide continuous input and feedback at the local and state level to develop or re-design services that will meet their employment needs.
Economic Environment	Unprecedented agency growth, coupled with a vigorous labor market, afforded the average worker good wages/benefit packages.	Agencies face reduced federal and state funding. Rehab Act Amendments make it easier to establish eligibility for services. Increased demands for services. Employment market changes. Fewer jobs at entry/semi-skilled level exist that offer living wages and benefits.	For those who require supportive services, rehabilitation specialists will be available to assist in providing vocational information, identifying supportive services, and securing employment.
Access	Focus was on correcting or minimizing the effects of an acquired disability (blindness, amputation, hearing loss, etc.)	Advocates representing various disability groups influence the expansion of rehabilitation services with an emphasis on employment (e.g., learning disability, sickle cell anemia, cerebral palsy, epilepsy, substance abuse, emotional impairment, deaf, etc).	Consumers become greater self-advocates and less dependent on others.
Eligibility	Rehabilitation used the medical model as the basis to determine eligibility. Emphasis was on client limitations.	Anyone with a disability who requires VR services to become employed is eligible for those services.	There will be the attitude that anyone who wants to work—can work!

	Past (1960-1992)	Present (1992-1996)	Future (1997 & Beyond)
Diversity	Some people with severe disabilities were determined ineligible for services. People with disabilities from different cultural backgrounds were not served at equitable levels. There was clear and measurable disparity in access to services, inclusion, service delivery patterns, monies spent per consumer, types of jobs at closure, and earnings.	Rehab Act Amendments cite disparities. Charge VR programs to develop strategies to build staff skills needed to effectively work with people from diverse cultural backgrounds, enhance outreach, service delivery, and successful outcomes to people from diverse cultural backgrounds.	Value cultural differences. Use culturally appropriate counseling techniques that facilitate trust and a sense of full partnership in the counseling relationship. Qualified staff can coordinate supportive services that create the opportunity for employment success in all areas of the labor market.
Special Programs	Vocational rehabilitation developed special programs based on the availability of targeted "federal or grant monies." The dollar drove the program!	The individual and the community assist in developing programs to meet the needs of people with disabilities.	People with disabilities who have the capacity, or who personally desire to do so, will design, coordinate and obtain employment-related services with or without the direct assistance of a rehabilitation/employment specialist.
Outcomes	Emphasis on process (statuses). Rehabilitation Closures "26s."	Emphasis on process (statuses). Rehabilitation Closures "26s." Focus on customer satisfaction, employment outcomes. There is less emphasis on rehab process indicators. "Jobs, jobs, jobs!"	Consumers have more choices. Determine own service plans and coordinate own services that enhance employment outcomes. Process indicators will have diminished importance. The measurable goal will be a "satisfied customer" who has achieved employment as a direct result of vocational rehabilitation participation.
Vocational Counseling Approaches	Counselors solved the problems, provided the answers. Were "fix-ers" and "do-ers."	New skills learned and employed, e.g., collaboration, negotiation, full partnership.	Vocational rehabilitation counselors will provide assessment, vocational guidance and counseling services to all in need of employment services. Additional access and equity in general employment.

	Past (1960-1992)	Present (1992-1996)	Future (1997 & Beyond)
Transition	Parents were reliant on the schools to care for children/students with special education needs. The emphasis was on providing developmental experiences. Expectations for employment and independence were held by parents, students, or schools.	The student, parents, vocational rehabilitation, schools, and employers collaborate to provide services to meet student/consumer employment goals and dreams. Transition services provided for both the student and parents.	Employment is an expectation and is achieved. Students, parents, schools, and vocational rehabilitation work cooperatively through mutual respect to prepare students/consumers for employment.
Community Integration	People with severe disabilities living in health care facilities depended upon the health care providers for assistance in daily living activities. Dependency mutually encouraged.	Independent Living Centers assist persons with severe disabilities achieve independent living. Self-advocacy a key principle. State Independent Living Councils provide continuous input to vocational rehabilitation.	Greater influence in designing rehabilitation services at the community level. Society fully respects and values people with disabilities as reflected in the diminishment of barriers both physical and attitudinal.
Empowerment	Persons with disabilities were dependent on the "kindness" of others to help them function in society. The professionals knew what was "best," and persons with disabilities trusted and depended on the social workers, teachers, therapists, etc.	Persons with disabilities demand and expect greater control of their destiny as it relates to education, employment, housing, independent living, and full partnership in the rehabilitation process. Self-reliance, civil rights (ADA), and empowerment are key principles that persons with disabilities fully embrace. Rehabilitation services acknowledge these values and reflect them in program designs.	Empowerment and self-determination. Full access to employment. Societal, attitudinal and architectural barriers removed. Choices. Full acceptance and respect.

1980s: New Initiatives, Partnerships, and Empowerment

The success of the 1970s provided the foundation for continued expansion with changing service delivery patterns and growing expectations in the 1980s. Pilot programs had proven that even persons with the most severe disabilities had both the desire and the ability to work. The integration of children with disabilities into public education settings with PL 94-142 demonstrated the value of inclusion. Disability groups who were previously seen as not employable or not eligible for vocational rehabilitation services began both to request and to demand access to vocational rehabilitation. The federal response (1985-1995) has been the sponsorship of major multi-year systems change initiatives in supported employment, school to work transition, and assistive technology. These initiatives were and are designed to (a) help the vocational rehabilitation system acquire knowledge and skills to serve expanding and new populations, (b) build partnerships among rehabilitation agencies and business and other groups to develop jobs, and (c) provide individuals with disabilities and their families with information and the skills to effectively direct and/or advocate for necessary accommodations and services to reach employment or other life goals.

It is important to note that over the last 20 years the perception and profile of persons served by vocational rehabilitation agencies across the nation have changed dramatically. Persons with mild disabilities needing minimal preparation for employment who were served during the 1970s began in the 1980s to be integrated into other public and private job training programs, e.g., JTPA, workers' compensation. Increasingly, referrals were made of persons with substantial and multiple disabilities who expressed a desire for work. These persons saw themselves as very capable of working. They perceived their disability not as a barrier to employment, but as a natural condition that could be addressed through attitudinal changes and/or technological accommodations to the environment. They also saw themselves as consumers of vocational rehabilitation services with the right to individualized services designed for them and evaluated by them.

The 1980s was also the decade of establishing new partnerships and restructuring rehabilitation in order to obtain and leverage resources needed to meet the growing costs and needs of people with disabilities. Interagency agreements with schools and community mental health programs to fund jointly a redesigned service system were initiated. In many communities innovative programs were initiated at the local and/or state level to address problems of service access and equity for target populations. Models for partnership between vocational rehabilitation and the business community were developed to address changing trends in the labor market and to secure financial resources to support inclusion of persons with disabilities in the work force.

Although vocational rehabilitation made significant progress in serving many populations through the 1980s, minorities with disabilities remained significantly underserved. Studies have documented the inequity in service access, case expenditure, and successful outcome:

- African-Americans make up 19 percent of all persons within working age who have disabilities, yet they represent only 8.6 percent of the year-round full-time workers with disabilities (Bowe, 1990).

- Nonwhites have a higher than proportional representation than whites among those closed 28 and 30 (nonrehabilitated) with the most often reported reason being "failure to cooperate" (Ross & Biggi, 1986).

1990s: Benchmarks–ADA, the 1992 Amendments, and State Advisory Councils

The growing expectations, collective voice, and political influence of consumers became evident in the early 1990s with the passage of the Americans With Disabilities Act (ADA) and the Rehabilitation Act Amendments of 1992. The Americans With Disabilities Act, signed by President Bush on July 26, 1990, made it unlawful to discriminate in employment against a qualified individual with a disability. The ADA also outlawed discrimination against individuals with disabilities in state and local government services, public accommodations, transportation, and telecommunications. This legislation is often called the civil rights act for persons with disabilities.

The 1992 Amendments to the Rehabilitation Act of 1973 were signed by President Bush on October 29, 1992. This act was more than a reauthorization or continuation of the Federal/State Rehabilitation Program. Instead it called for substantial adjustments in the principles, purpose, process, and outcomes of the rehabilitation program to support persons across the full range of type and extent of disability to attain and maintain employment outcomes appropriate to the consumers' interests and abilities. The Rehabilitation Act Amendments put the abilities and choices of persons with disabilities first and challenged the services system and the greater community to support their efforts to work, live, and participate in the community (Revell, 1993). Most importantly, the Amendments re-established that employment outcomes are the primary purpose of the public rehabilitation program.

In order to address the recognized concerns about service to and the involvement of minorities in rehabilitation service design and delivery, Section 21 of the 1992 Amendments called for a renewed focus on people from racial and ethnic minority groups. Vocational rehabilitation agencies were directed to develop strategies for outreach into minority communities, to build the cultural competency of existing staff, and to recruit staff from diverse cultural backgrounds. In addition, Section 302(a)(4) of the Act requires the provision of grants to institutions of higher education with a minority enrollment of 50 percent or more to assist in the recruitment and preparation of students for careers in vocational rehabilitation

In addition to its efforts to enhance minority involvement in and receipt of quality services, the 1992 Amendments to Title I of the Rehabilitation Act introduced far-reaching provisions to assure that individuals with disabilities have a strong and substantive role in shaping vocational rehabilitation programs to support their aspirations. The establishment of the State Rehabilitation Advisory Council (SRAC) provides a formal mechanism to influence systems and policy direction. This body is assigned several important and significant functions that will be fully examined in Part II of this document.

The statutory provisions made the council an advisory body with a degree of independence through:

- Assigning the state, through its governor, the responsibility for appointments

- Designating a vocational rehabilitation administrator as ex-officio or nonvoting member

- Requiring resolution of disagreements about council and vocational rehabilitation agency functions by the governor or appointing authority

- Directing vocational rehabilitation agencies not to assign duties, which might create a conflict of interest to staff supporting the council

- Outlining a role for the council in the hiring and evaluation of designated staff

- Requiring the development of a distinct budget adequate to carry out the duties of the council

The Present and the Future

Since 1992, rehabilitation agencies across the nation have worked to continue or to initiate activities and relationships with consumers that reflect the changing roles communicated in these important legislative benchmarks. Significant legislative and programmatic changes are taking place at the federal level. The current political environment is one of close scrutiny in order to determine how to utilize shrinking resources to meet vocational rehabilitation, other work force development, and human services needs. These efforts to streamline government are having and will continue to have a significant impact on federally funded programs that serve persons with disabilities.

The 1992 Amendments to Title 1 of the Rehabilitation Act share important concepts related to assuring effective services and employment outcomes for all people including those with disabilities. The common concepts that can lay the foundation for alliances that must be formed between rehabilitation professionals, consumers, and the general public include:

- Streamlined, responsive, customer-driven service delivery systems

- User friendly services based upon consumer choice and consumer satisfaction

- Direct local access to services

- Equity of services

- Service integration and collaboration

- Public-private partnerships

- Focus on employment outcomes

- Use of advisory councils to develop short- and long-range plans for service delivery

The involvement of vocational rehabilitation professionals and advocates in the broader political environment also requires a strengthened partnership and approaches different from those used to date. Vocational rehabilitation agencies must continue to work to develop programming and decision-making processes that are based upon consumer input and consumer satisfaction. The person with a disability, willing to undertake the partnership role, must be prepared to face an almost incredibly diverse array of competing public and private interests, all with their own goals, and many with equally compelling claims upon the public purse. To prevail, persons with disabilities and their advocates must be open to dialogue and compromise with not only competing interests but also public policy decision makers. This is a far more daunting, difficult, and crucial role than mere networking between disparate factions. Leadership is required.

Creative and cooperative partnership among consumers, vocational rehabilitation, and major stakeholders will provide the collective strength and voice needed to ensure that people with disabilities will have equal and full access to rehabilitation resources and qualified rehabilitation professionals who can deliver individualized and specialized services.

Part II

Consumer Involvement

How to Make it Happen

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How to Make It Happen

Introduction

Drawing on the vision and values as well as the perspective presented in Part I of this document, Part II provides "how to" information to assist vocational rehabilitation (VR) agency staff to enact steps to promote persons with disabilities as partners and leaders in the decision making, policy development, and policy implementation that shape the direction of state vocational rehabilitation programs. This section will identify strategies for meaningful involvement of individuals with disabilities and will examine make-up, roles and responsibilities, recruitment, and operational strategies. Attention will also be given to consumer involvement strategies such as legislative advocacy, leadership skill building, personal development, training, planning, and evaluation that can enhance the vocational rehabilitation state program beyond advisory council meetings. Each recommended strategy will be presented in bold face and then discussed.

Part II will be followed by resource information about successful consumer-agency partnerships. Information will include state contacts who have experience in the implementation of a particular strategy. The Prime Study Group provides the examples to assist in efforts to strengthen existing partnerships. The examples utilized are by no means the only ones that exist throughout the nation, but those we were able to identify in the time available.

The Prime Study Group is hopeful that this document will be used by readers to build local, regional and/or national networks where ideas and strategies can continue to be shared via E-Mail, phone conference calls, or face-to-face discussion.

"Top-Down" Endorsement Strategies

Leadership was identified in Part I of this document as a foundation value for meaningful consumer rehabilitation partnership. Leadership is most evident when there is clear, consistent, regular, and reinforced top-down endorsement of the membership and activities that support the partnership of state and agency leaders. A number of strategies can be used to demonstrate this top-down endorsement.

Efforts should be made to educate and influence the state legislators and officials who have an impact on the vocational rehabilitation programs about the desirability of consumer involvement and direction. Governors appoint members to advisory committees and in most states either appoint or approve the selection of the state rehabilitation agencies' (i.e., general agency and blindness agency) directors. The administration provides leadership for the inclusion of persons with disabilities as full partners and must convey this attitude of acceptance and support of the partnership in as many ways as possible.

Agency administrators must show their commitment to consumer partnership efforts via clear initiatives and the allocation of adequate resources (people, time, supplies, etc.) to carry out activities designed to facilitate the involvement of individuals with disabilities. For consumer involvement to be truly meaningful, this commitment should pervade the entire state rehabilitation system. The agency leadership may initially communicate its commitment to these efforts through the development and distribution of a policy statement on consumer involvement to all agency staff and other stakeholders (e.g., consumers, families, advocates). Implementation of such an initiative would require consumers and staff to jointly establish goals, benchmarks for improvement, and a plan of action for accomplishment. The development of a written plan for involvement is one way to assure that all agency staff can access the state position. The development of a plan with high levels of consumer involvement as well as the strong promotion of its adoption by state directors and supervisors is critical to conveying the type of commitment being discussed here.

For an example of a written approach, the reader is directed to review the *Program Statement and Plan in Consumer Involvement* developed by the Massachusetts Rehabilitation Commission contained in the Resource Section (see Resource A). The preface clearly indicates the state administrator's commitment to the philosophy and the following sections detail ways that a high level of involvement by persons with disabilities will be used to successfully shape the direction of the state program. The importance of this high level of support for consumer involvement *cannot* be overstated. The allocation of people, time, supplies, and other resources to facilitate improved and increased consumer involvement is an essential foundation for all the recommendations made in this document. The importance of this commitment and support will be referred to several times throughout this section as related to the various activities, functions, and roles consumers and consumer groups will play in the process.

The development of a diversity profile and action plan by agency leaders will enhance partnerships by assuring the inclusion of persons from diverse backgrounds within the agency/unit work force and consumer leadership group. A diversity profile and action plan is designed to ensure that the agency is inclusive and representative of the community as a whole by examining the diversity of the agency's staff in terms of disability status, race, ethnic origin, gender, and sexual orientation. In most states, it will be necessary to do regional profiles since metropolitan areas may have a significantly different population makeup than rural areas. Rehabilitation state agency administrators need to work closely with rehabilitation counseling training programs and their state personnel office to recruit potential staff into the profession from groups that are underrepresented in the agency. One of the best ways to ensure that people with disabilities are actively involved in agency decision and policy-making is to hire qualified people with disabilities for management and professional level positions. There must be a sincere commitment to the vision and values that the state agencies will be *improved and strengthened* through establishing and maintaining staff diversity.

The Resource Section of the document provides information on the objectives, activities and outcomes of the Michigan Multicultural Task Force in existence since 1985. The Multicultural Task Force (see Resource B) concentrates its activities into four principal areas:

1. Policy dissemination to ensure that managers understand the multicultural policy and incorporate it into their annual work plans.
2. Monitoring development of a mechanism by which performance in serving culturally diverse populations can be accurately evaluated.
3. Staff development through expansion of training for all staff to build cultural awareness and the effective skills required to work successfully with people of differing cultures.
4. Organization and development to address work force diversity issues and service delivery.

Involvement via Statewide Councils

This section will share the point of view of one vocational rehabilitation director who has experience with true consumer decision making. Strategies will be suggested to maximize the effectiveness of the councils in the general areas of staff support, member recruitment, and council operation. When appropriate, the reader will be guided to additional information providing examples of successful implementation of the strategies presented.

THE POWER OF COUNCILS - ONE AGENCY DIRECTOR'S PERSPECTIVE

Formal advisory councils were not addressed in the Title I regulations or required for a general vocational rehabilitation program until 1992. This does not mean that advisory councils are a new idea. Many vocational rehabilitation agencies have used formal or informal groups to gather input in planning. What is new and different for most directors is the very real authority given to the group.

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Initially, creation of an advisory council or a consumer-controlled board may create fear for a vocational rehabilitation or other agency. This is a natural consequence of giving up power and control for any group, organization, or individual. However, history has shown that in agencies where this has occurred, persons with disabilities can make the same decisions, whether agency-level policy decisions or individual choices, that rehabilitation professionals would make given that they are provided the same information. As a SRAC they are required to work within the framework of the law and regulations, just as are rehabilitation professionals. When vocational rehabilitation consumers assume the role of an advisory council or controlling board, they take ownership of the policy decisions of the agency and no longer need to accept things having been done to them or being imposed upon them. Vocational rehabilitation consumers move from being critics of policies of the agencies to being their greatest supporters, defenders, and allies. After all, the policies are now *their* policies—not those of a bureaucratic state agency.

In no agency is this more evident than the Oregon Commission for the Blind. The Oregon Commission for the Blind, since 1978, has been managed by a seven-member consumer controlled board responsible for hiring the administrator and for guiding agency direction. Chuck Young became administrator in 1980 and initially expressed concern about the groups' ability to overcome competitiveness in order to reach a consensus on major functions. This competition was never realized and fears among the leadership disappeared within the first year. Today Chuck Young (personal communication) states that "*consumer controlled agencies and services create the ultimate investment and ownership by persons with disabilities in the outcome of services and the agency*."

State Rehabilitation Advisory Councils: Makeup, Role, and Responsibilities

Members of a State Rehabilitation Advisory Council (SRAC) shall be composed of:

1. At least one representative of a parent training and information center.
2. At least one representative of the client assistance program.
3. At least one vocational rehabilitation counselor who shall serve as an ex officio, nonvoting member of the Council.
4. At least one representative of community rehabilitation program service providers.
5. Four representatives of business, industry, and labor.

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6. Representatives of disability advocacy groups representing a cross section of
    a. individuals with physical, cognitive, sensory, and mental disabilities
    b. parents, family members, guardians, advocates, or authorized representatives of individuals with disabilities.
7. Current or former applicants for, or recipients of, vocational rehabilitation services.
8. The director of the designated state unit shall be an ex officio member of the Council.

A majority of the SRAC members shall be persons with disabilities as defined by the Rehabilitation Act of 1973 (as amended).

It should be noted from the above that the SRAC includes a broad range of constituent representatives who may not necessarily be consumers (or clients) of the state-federal vocational rehabilitation program.

The State Rehabilitation Advisory Council is established to influence the direction of the vocational rehabilitation program and broader rehabilitation services and concerns within each state. Tables 2 summarize the roles and responsibilities of the Council.

Table 2. Summary of Functions of the Statewide Rehabilitation Advisory Council (SRAC)

Influencing Vocational Rehabilitation and State Policy and Services

- Review, analyze, and advise the designated state unit regarding performance with particular attention to:
    - Eligibility (including order of selection)
    - Extent, scope, and effectiveness of services provided
    - Functions performed
- As possible, evaluate *program effectiveness* and *consumer satisfaction* of all federal and state-funded rehabilitation services provided by vocational rehabilitation and other agencies.
- Make recommendations to the governor, on a yearly basis, regarding the effectiveness of rehabilitation services in the state.
- Assist in the development of the state plan for service provision, the strategic plan, and amendments to the plan.

Partnerships and Coordination

- Coordinate with the State Independent Living Council (SILC).
- Coordinate with other councils within the state including the Developmental Disabilities and Mental Health Councils, an advisory group established under the Individuals with Disabilities Education Act (IDEA).

Council Support Strategies

The authors of the 1992 Amendments to the Rehabilitation Act of 1973 mandated that resources be made available to conduct the business of the councils. Required resources include funds and personnel that must be conscripted or made newly available to support the increased functions and operation of the councils.

1. **Create a position/job description to support council and related consumer partnership building activities**. It is the feeling of the Prime Study Group that state agencies allocate one full position (e.g., liaison) to the development of consumer partnerships through councils and beyond. This recommendation calls for true commitment on the part of the vocational rehabilitation agency or unit through the allocation of *real* time on the part of the staff person to address the needs and activities of the SRAC as well as the additional activities undertaken in the name of enhanced consumer involvement. Simply adding responsibilities to an already overly committed staff person will not be sufficient to meet the need. It is also essential that the individual be given the clear responsibility to help a council to do its job. This person must not be placed in situations where there is the possibility of a conflict of interest between the agency and consumer leadership.

The staff liaison to the consumer councils should have credibility within the disability community as well as possess a thorough understanding of the state-federal rehabilitation program. There must be regular communication with people with disabilities to provide direction and input into program planning activities, allocation of agency resources, and evaluation of agency performance. The staff liaison is the logical first step in this communication chain.

Major components of a liaison's job description are provided in Table 3 for use in developing or adapting a similar staff position. The resource section of this document lists the State Rehabilitation Advisory Councils (see Resource C). The reader might use this list to contact other states to learn more about their efforts and activities with consumer councils.

Table 3. Sample Job Responsibilities for the Consumer Involvement Staff Person

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Responsibilities Related to Consumer Identification and Involvement

- Assists regions to identify, develop, and support consumer advisory councils and committees.
- Develops regular tools for the recruitment of consumers and provides either short-term or ongoing communication opportunities that affect vocational rehabilitation or independent living services.
- Assists in design, implementation, and analysis of consumer satisfaction measures.

Responsibilities Related to Consumer Advisory Council Functioning

- Facilitates the agency-council partnership in the recruitment and orientation of council members.

- Assures that council functions are performed in partnership through developing and maintaining mechanisms for establishing regular meeting agendas and ongoing functioning of council sub-committees.
- Arranges for all supports to maximize involvement of council members.
- Arranges for all supports needed for public input by consumers.

Responsibilities Related to Relationship Building with Consumer Organizations

- Maintains an understanding and working relationship with consumer organizations in the state.
- Establishes and facilitates intergroup communication and planning with consumer groups.
- Administers any contracts related to consumer involvement activities initiated to accomplish identified goals.

Council Recruitment Strategies

Discussion thus far has centered on the functions and responsibilities of the mandated advisory councils as an obvious vehicle for enhancing the involvement of individuals with disabilities in the shaping of vocational rehabilitation programs. What about efforts to assure that all persons with disabilities have access to advisory council involvement? The vision and values that support this document call for the opportunity for *all* persons with disabilities, regardless of their specific disability, to become involved at their level of interest and satisfaction.

1. **The agency must adopt an attitude of inclusion and make an effort to bring to the advisory table persons who have not been there before**. This is a multistep process. The initial step is recruitment. The state councils described earlier are populated by people who have been appointed by the governor or state legislative unit. Real efforts must be made to reach those consumers who have not typically been noticed in their states.

Recruitment of these members can be accomplished by contacting state associations of persons with disabilities for recommendations. Many states have a list of formally organized groups; this list can be obtained by contacting either the secretary of state's office or the vocational rehabilitation unit. There is often a master list used for mailings that includes all known organizations and associations of persons with disabilities. Parent and family associations should also be contacted for members, referrals, and recruiting assistance.

2. **State advocacy organization leaders must contact their governor's office to request consideration for appointment to the council(s)**. As the advisory councils mandated by the 1992 amendments are already in place, contact should be directed to the vocational rehabilitation agency unit. When a national headquarters exists, contact might also be made by the executive director or president. For example, during the time that the SRACs were being appointed, the National Association of the Deaf (NAD) contacted the presidents of their state associations and encouraged them to contact their governors. At the same time, NAD also contacted the governors of each state directly to remind them of the need for deaf and hard of hearing interests to be represented and provided the name of the state association president for future reference and contact. This effort resulted in unsolicited responses by nearly one-third of the governors' offices, resulting in

the appointment, or confirmation of a previously appointed member, of deaf and hard of hearing persons.

3. **Multiple representatives of consumer groups should be recruited and included on the councils.** True adherence to the values of involvement of persons with disabilities in shaping a vocational rehabilitation program does not allow for tokenism in either the number of persons with disabilities chosen to serve (i.e., one person from a particular consumer group) or the amount and kind of tasks assigned to the people (Valentine & Capponi, 1989). Tokenism is abolished in a situation where true partnership is the goal. The issue of group size is addressed in a following section at greater length.

4. **Members of the existing councils should be encouraged and assisted to identify and to mentor future members.** In recruiting members, especially those who may be new to the venture, provide a full and accurate description of the role and responsibilities of the membership. A current member is the best person to provide that description as well as to assist a new person with advocacy and advisory skills needed for success in the role. An effective resource is found in a publication by Pederson and Chaikin (1993) *Voices That Count. Making it Happen: A Presenter's Guide*. This training package is designed for use by persons with developmental disabilities to learn the skills necessary to become a full partner in advisory groups.

Council Operation Strategies

After recruitment, involvement in shaping vocational rehabilitation programming will additionally require that concerted effort be made to assure that council members have the opportunity for *meaningful* involvement in council meetings and related activities. This is especially true in the case of persons with communicative difficulties. In 1993, the Prime Study Group for the Nineteenth IRI addressed consumer involvement and recommended:

> Although consumer involvement is not a new concept, it is still an unresolved issue because consumers have never been successfully blended into the rehabilitation research and practice process. The successful integration of consumers in rehabilitation research and practice depends on the provision of professional training and technical assistance, because consumers need assistance in developing skills required for successful interaction and participation [in a system that they have typically experienced from only one side]. . . . [All] must strive to obtain the information necessary for the successful implementation of a cooperative working relationship. (p. 78)

Application of this principle to the conduct of the council meetings will require preparation and accommodations on the part of all who will participate. Special attention will need to be given to assure that people with various communication disabilities are accommodated in such a way that their input counts equally. This is particularly true in situations where the disability affects cognitive processes (e.g., developmental disabilities), communicative ability as with deaf and hard of hearing people, persons with speech impairments, and persons with cognitive processing difficulties or disfluencies. While not advocating that each and every disability special interest be represented, efforts should be made to assure that often overlooked groups, especially those representing individuals who experience cognitive and communicative difficulties, are included.

1. **The advisory council should utilize a committee structure to maximize effectiveness and member involvement**. The mandated advisory councils make no maximum size recommendations but call for the appointment of targeted representatives. It would be impossible to include every specific disability group and all interested people without resulting in large unmanageable meetings. The council organizers might best go to a committee structure whereby the bulk of the work is completed by persons in smaller groups and the full council meets on a less frequent, and more focused, basis. This approach allows for more work to be accomplished in depth. More meaningful input can be achieved from reports presented by teams of people who have closely examined the issues and prepared recommendations for the full group.

Committee work also allows a more accessible format for assuring inclusion and involvement by providing smaller forums in which to communicate ideas. These smaller groups require less time per meeting as compared to a large meeting with a long agenda. Such a committee approach might divide the various functions of the state agency into topics (e.g., staff development, program services, innovative programming, etc.). Committees could be assigned to deal with each topic and meet on as frequent a basis as may be needed by the group. These smaller groups also require less time per meeting while still addressing their entire agenda.

2. **Establish rules to guide council meeting operation**. Steps need to be taken to assure that the meetings are forums where all voices are heard—not just the voices of the most aggressive. The basic functions of meetings include providing a place where information and ideas that have been acquired separately (e.g., per disability groups or per subcommittee efforts) can be shared and exchanged (Eberhardt, 1985). Once shared, these ideas are discussed further and built to a group consensus for action. The full council meetings also serve to assist individual members to see how they fit into the larger picture and remind them of the agency's goals and parameters for provision of services. Rules must be set up in advance and agreed to by all members of the councils in order that all voices will be heard. An ineffective meeting is characterized by domination by any one person (even the chairperson!), clique, or other strongly coalesced group; arguing between members; or expression of ideas only without complementary expression of feelings being admitted (Eberhardt, 1985).

3. **Full council meetings should be scheduled to allow enough time to cover topics adequately and to allow all the chance to participate**. Short agendas and more frequent meetings are likely avenues to pursue to execute this recommendation.

4. **Maximize member involvement through accommodation and technology**. While there are a great many publications available on how to conduct effective meetings of boards and advisory groups, some basic rules apply and bear repeating here in relation to adaptations for involvement of individuals with disabilities. In general, the success of an advisory meeting is in the ability to get information, feedback, input, and consensus from among the members. This

means that all need to have an equal opportunity to share. An excellent resource that provides a tool for determining individual support needs was recently released by the Oregon Developmental Disabilities Council titled *Not Another Board Meeting! A Guide to Building Inclusive Decision-Making Groups* (Gobel, 1995). Minutes or note taking should occur at each meeting. Special efforts must be made to provide notes in a manner and time frame that make them most useful to the full involvement of individuals with disabilities. Provide appropriate interpreting services as needed to assure that persons for whom English is not a first, or most comfortable, language of communication are included (e.g., sign language and spoken foreign language interpreters, braille, large print). Physical surroundings should be accessible to persons using wheelchairs or other mobility equipment. This includes improving restrooms that all too often advertise accessibility but only achieve it at the cost of privacy and dignity of the persons having to use the facilities.

5. **Orientation and ongoing training should be provided to all members.** A brief list of suggested topics to be covered in orientation meetings is included in Table 4.

Table 4. Suggested Topics for Orientation Training

Explanation of State-Federal Vocational Rehabilitation Program

- The Rehabilitation Act and Amendments
- Terminology and acronyms
- How services are provided
- The Independent Living philosophy and program

Description of Advisory Council

- Function
- Role
- Responsibilities
- Operation

Ongoing training would occur during preview meetings scheduled just prior to the full council meeting (Pederson, Chaikin, Koehler, Campbell, & Arcand, 1993). The preview meetings would provide an opportunity for members to go over the agenda, to prepare for the discussion on each agenda topic, and to formulate their opinions or questions. Thus prepared, and more comfortable with what to expect in the meetings themselves, these members can participate more fully in the process (Pederson et al., 1993). One way to do this is to require the liaison staff person to schedule individual or group preview meetings.

6. **Match experienced advising council members (mentors) with new members to provide both training and personal assistance.** Using partners in this way would assist new

members to become comfortable with the situation. Mentors would serve to provide preview information and to assist new consumer members who may need additional information during the meetings in order to participate in a meaningful way. Partnering members also provides an avenue for each member to become more familiar with the other's concerns, needs, and issues in a way that will strengthen the representativeness of the group. Inclusion will take time and may cause frustration and setbacks. However, adherence to the basic vision and values of the importance of consumer input ameliorates these problems.

7. **Additional meetings should be scheduled to assist members who need the extra time to acquire effective meeting skills**. A rationale for this is presented in a wonderful chapter that discusses meaningful involvement of persons with mental retardation or developmental disabilities in advisory groups. See *Older Adults with Developmental Disabilities: Optimizing Choice and Change* (Sutton, Factor, Hawkins, Heller, & Seltzer, 1993) and the chapter, "Strategies that Close the Gap between Research, Planning, and Self-advocacy" (Pederson et al., 1993). This chapter presents a value framework similar to this IRI document: there is

> ...no question as to the importance of enabling people with mental retardation/developmental disabilities and their family members to determine their own futures .... There is, however, a question as to how they might influence policy-makers, planners, researchers, and service providers in the process .... A critical issue arises when people with mental retardation/developmental disabilities are placed in situations in which true partnerships do not exist and they are vulnerable to negative consequences when they do speak up. The potential for this type of situation can become a barrier to involvement. (p. 280)

To avoid these barriers, these members, as well as others (e.g., parents unfamiliar with vocational rehabilitation), may require additional training prior to involvement to help them become more comfortable with their role and the expectations of them in these meetings and beyond.

8. **Acknowledge consumer member contributions through financial support**. This recommendation relates to the earlier issue of agency commitment of resources and financial support. The Prime Study Group strongly recommends this strategy in recognition of the importance of the participation and contribution of the individuals with disabilities to the shaping of the program. Resources must be made available to reimburse travel expenses, reimburse for lost pay if necessary, cover child care expenses (unless child care is provided during meetings at no charge). The value of their contributions must be acknowledged directly and as quickly as possible. Many times the "grass roots" persons with disabilities who are desired for these meetings cannot attend them if the funds are not provided either in advance or at the meeting.

It is also strongly suggested that refreshments and frequent breaks during these meetings not be overlooked. Extra time, attention, and concentration calls for extra fuel. Agency policies for provision of food at meetings should be reviewed and adjusted as necessary to provide what is needed.

Partnership Beyond The Councils

Advisory council participation is only one avenue for meaningful consumer involvement and impact in the shaping of vocational rehabilitation programs. True involvement goes far beyond quarterly meetings. Meaningful impact calls for more to occur. In addition, vocational rehabilitation agencies will wish both to utilize Council members effectively and to draw from a much broader base of present and future consumers for participation in planning, implementation, monitoring, and evaluating of rehabilitation services. This section will suggest strategies for a consumer agency partnership related to (a) legislative advocacy and networking strategies: (b) personnel development strategies; and (c) state and/or local planning, policy development, and evaluation strategies.

Legislative Advocacy and Networking Strategies

Consumer-council members can and should be leaders in presentation and support for essential effective rehabilitation services. It is incumbent upon vocational rehabilitation staff to prepare and support them in this important role.

Make vocational rehabilitation participants and council members effective agency advocates in the legislative process. Targeted consumers from across the state should be invited to participate in training and orientation that will help them understand the key state leaders, the decision-making process, major budget information, and significant agency performance measures. It is recommended that this training occur at the state capitol so individuals can become aware of the physical site and prepare for accommodations necessary on future visits. Training may be most effective when done in partnerships with local advocacy organizations that can effectively provide tips on letter writing to key decision makers or provide voting records on significant issues.

Enhance the visibility and leadership opportunities of targeted council members and other consumers. Vocational rehabilitation leaders should consciously work to increase the visibility and credibility of their council member partners. Any effort that makes the council chair known as an effective and reasoned advocate in a nonlegislative year will pay off when the time comes. Some activities designed to enhance visibility may include (a) establishing and using council letterhead for all major communication, (b) inviting a state leader to each council meeting, (c) putting a regular Advisory Council update in statewide consumer and/or vocational rehabilitation publications, and (d) encouraging council member participation in generic statewide activities e.g., work force development sessions and general community forums.

The issue of leadership by individuals with disabilities is central to the vision and values that underlie this document and the recommendations within this chapter. Most leaders are not born: they become leaders through a variety of life situations. Individuals with disabilities are not often presented with the opportunities to develop the skills to become leaders. However, we will ask them to develop these skills through involvement in the shaping of the vocational rehabilitation program. How is this gap bridged? How are leadership skills acquired and fostered within the disability community?

The entire focus of an excellent publication released by the University of Minnesota Institute on Community Integration and the Research and Training Center on Residential Services and Community Living (see Resource D) is leadership by persons with disabilities. This informative issue features articles on leadership by persons with disabilities: past, present and future; culturally diverse leadership; civic leadership; and leadership through community service. Given its focus on how people with disabilities can assume and are assuming leadership roles in shaping agencies and programs, this entire issue should be required reading for all agency and unit personnel as well as for members of advisory councils.

Continuously work to strengthen the network between consumers and state agency staff. This will be accomplished through implementation of most or all of the major strategies discussed throughout this document. Worth special mention is agency support for staff involvement in consumer advocacy or other related organizations. Such involvement should be required for all counselors and administrators. Involvement in local organizations should be supported, encouraged, and recognized for staff at all levels. Active participation by vocational rehabilitation staff in a consumer-controlled and directed conference through presentations, social hours, etc., demonstrates the agency commitment to equality. In addition, assignment of State Advisory Council members to specific vocational rehabilitation offices with regular invitations to attend staff meetings, open houses, etc., will increase knowledge and understanding of all partners in the process.

Work to assist consumer partners in effective communication with various constituents. This may mean providing office space or printing funds to help develop a newsletter or conduct monthly forums or other meetings of individuals with disabilities. All staff, including the liaison, should allocate a percentage of their time to working with local advocacy organizations and consumer groups. Counselors and other direct service staff should be encouraged to be actively involved in community grass roots efforts to develop and improve consumer-driven services. The vocational rehabilitation agency or unit should invest time and resources in the development of individuals with disabilities as constituency leaders. Perhaps assistance in overcoming the nervousness that comes before addressing a group of state legislators might be offered. The agency staff might copy documents to be handed out to legislators or provide assistance in developing a position paper and writing it for distribution. Whatever the task requested, the agency needs to be ready to support the development of leadership skills of their partners. This can be accomplished through the staff liaison and others with particular skills (e.g., grant writing) that may be identified and recruited to the task.

Personnel Development Strategies

The recently drafted code of federal regulations included personnel development activities as an identified function of the State Advisory Council. Utilization of consumers at all levels of these activities is an effective demonstration of the top-down commitment to equal partnership discussed earlier in this document.

Involve consumers in human resource/personnel development activities related to hiring, training, and evaluating present and future agency personnel. The individuals with disabilities should provide at least yearly input in the establishment of training plans, goals, and priorities for vocational rehabilitation staff. These partners should further be involved in the delivery of this training, as well as the evaluation of its impact on service improvement and staff performance.

Encourage council member participation in regular ongoing training provided as preservice or in-service for vocational rehabilitation staff. Involvement in this training not only increases understanding of the vocational rehabilitation process but builds essential networks between staff and council members. In this partnership either party should be able to go to the other with questions or concerns designed to increase the effectiveness of rehabilitation services.

As important as consumer involvement is in training of existing vocational rehabilitation staff, it is equally important they assume an active role in the training of the professionals of the future. Persons with disabilities should be essential participants in the training that helps create the brokers, negotiators, and facilitators who believe in, understand, and support the values of consumer independence, inclusion, empowerment, and self-determination.

Consumers must be involved in both the hiring and evaluating of staff assigned responsibility for support to Advisory Councils. In some states the councils or designed consumers have a legally mandated role in the hiring and firing of the agency administrator. Utilization of council members or other consumers as a partner in this process for all staff levels is seen as an effective means of strengthening the responsiveness and customer-driven nature of the agency.

State and/or Local Planning, Policy Development, and Evaluation Strategies

Encourage and support effective consumer involvement in local or state public hearings, town meetings, or focus groups. Consumers can be expected to have ongoing involvement in vocational rehabilitation activities related to planning and/or policy development. To provide essential customer-based input to time-limited topics, specific work groups, or focus groups may expand or supplement the work of the advisory council. For example, it may be appropriate to establish consumer work groups that focus specifically on the needs of newly emerging disability groups (e.g., HIV/AIDS) or underserved populations (e.g., people of color with disabilities). Council members may co-facilitate the leadership of such efforts along with designated agency staff.

Public hearings are often scheduled in order to gather specific or general consumer input to draft policy and/or agency planning and direction. In these cases the effectiveness of consumer input will be enhanced when notices are sent early and include the questions that will be asked or information that is to be reviewed. This allows participants to adequately prepare for meaningful involvement. Attention to meeting location, date, time, and personal accommodations available will also help to maximize participation.

Consumer involvement in shaping state programming is critical in the process of evaluation. Consumers should be utilized as not only recipients of services but also excellent resources for gathering the mandated satisfaction information from other consumers around the state. The value of having consumer-council members as interviewers and data collectors cannot be overstated. Their involvement in interpretation of results will also prove valuable to program developers and state agency administrators.

Conclusion

The need for involvement of individuals with disabilities in shaping vocational rehabilitation programs has and will continue to be very important. These partnerships are essential to assure continued quality services, the identification of needs, and the receipt of full benefits.

Part II provided some suggestions for ways to enact this commitment to the vision of involvement and partnerships. Throughout the chapter, the need for top-down commitment and support via funds and personnel was cited as critical to the success of this necessary and mandated endeavor. The suggestions should serve as a starting point. State agencies and units are encouraged to take them and go far beyond these efforts to assure true and meaningful collaboration with persons with disabilities in program endeavors. Attention should be given to the resources provided in the appendices of this document. Together they should help each reader take the next steps toward reaching the vision of full and equal partnership in his or her state.

Part III

Resource Section

Resource Section

In writing this book, the Prime Study Group gathered ideas from many individuals all over the country. The strategies presented in Part II were an initial effort to compile good ideas, but of course it is not a complete listing of strategies. We hope we have increased your awareness and interest in brainstorming about consumer involvement. In this resource section, we also want to provide you with names of people you may wish to contract for further information.

States With Strong Consumer Involvement Programs

The following states have full time positions and programs that focus on consumer involvement.

Gene Defabio
Consumer Affairs Coordinator
West Virginia Department of Education and the Arts
Division of Rehabilitation Services
State Capitol
P. O. Box 50890
Charleston, WV 25305-0890
(304) 766-4671

Mr. Erneka Nwokeji
Director, Consumer Involvement
Massachusetts Rehabilitation Commission
Fort Point Place Suite 600
27-43 Wormwood Street
Boston, MA 02210-1606
(617) 727-8418

Models for Program Evaluation Consumer Satisfaction

Oregon has established a statewide system of benchmarks for the development and measurement of a quality of life and a quality workforce in the state. This includes established performance measures for consumer and employer satisfaction within the Vocational Rehabilitation Division. In addition, The State Rehabilitation Advisory Council developed and distributed a survey of state and community rehabilitation agencies to identify major accomplishments, issues, the use of tools to measure consumer satisfaction, and recommendations for improvement.

John Glen
Oregon Vocational Rehabilitation Division
Research and Evaluation
500 Summer Street NE
Salem, OR 97310-1018
(503) 945-6709

Wisconsin State Rehabilitation Program Advisory Council gathered input from customers by using a combination of written survey and phone call follow up. The survey was sent to 2010 closed vocational rehabilitation clients with a follow-up letter and phone call, if necessary. The three contacts resulted a 66 percent return rate.

Arvilla Rank or Glen Olson
Wisconsin Division of Vocational Rehabilitation
1 West Wilson Street
P. O. Box 7852
Madison, WI 53707
(608) 267-9110 or TTY (608) 261-6756

Resource A

Program Statement and Plan in Consumer Involvement

Massachusetts Rehabilitation Commission

BEST COPY AVAILABL

Massachusetts Rehabilitation Commission

Program Statement and Plan
in
Consumer Involvement

William F. Weld
Governor

David P. Forsberg
Secretary of Health and Human Services

Elmer C. Bartels
Commissioner of Rehabilitation

ELMER C. BARTELS
COMMISSIONER

The Commonwealth of Massachusetts
Executive Office of Human Services
Massachusetts Rehabilitation Commission

Fort Point Place - Suite 600
27-43 Wormwood Street
Boston, MA. 02210-1606

MASSACHUSETTS REHABILITATION COMMISSION'S PROGRAM STATEMENT AND PLAN IN CONSUMER INVOLVEMENT

DATE, 1992

Elmer C. Bartels

Commissioner of Rehabilitation

ELMER C. BARTELS
COMMISSIONER

The Commonwealth of Massachusetts
Executive Office of Human Services
Massachusetts Rehabilitation Commission

Fort Point Place - Suite 600
27-43 Wormwood Street
Boston, MA. 02210-1606

PREFACE

As is well known, I have a personal and professional commitment to the effectiveness of the Consumer Involvement Program at the Massachusetts Rehabilitation Commission. As a person with a disability, and longterm advocate of the Agency's services, I know how difficult it can be to make appropriate input into an agency's policy and programming. The point of view of a consumer has not always been valued the way I feel it should be. Therefore, since my appointment as Commissioner I have dedicated my efforts to change this situation.

I know it is not easy to change agency staff attitudes as well as those of previously unempowered consumers. Useful models had to be provided before the necessary changes in behaviors could be made to last. The Consumer Involvement Program has continued to provide opportunities for the growth of consumers as well as staff and the broader Agency publics. We can now see how the impact of consumer involvement philosophy nationwide has led to the recent passage of the Americans with Disabilities Act (ADA) -- the most far reaching civil rights act for people with disabilities ever passed in this country.

Described within this document is the evolution of a program which was once only a vision. It remains my vision to constantly improve upon and publicize the successes of our partnership with the consumer community.

I trust this description of the Consumer Involvement Program will give others an appreciation of how far we have come and the direction in which we intend to continue.

Elmer C. Bartels
Commissioner

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C. Northeast Regional Consumer Advisory Council

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MASSACHUSETTS REHABILITATION COMMISSION

PROGAM STATEMENT AND PLAN IN CONSUMER INVOLVEMENT

PROGRAM STATEMENT

Purpose

The primary purpose for the Consumer Involvement Program in the Massachusetts Rehabilitation Commission is to enhance and improve the Commission's service delivery system by working cooperatively with members of the disability community on projects of mutual interest. Federal and State rules and regulations require that the state agency for rehabilitation take into account the views of those who may be current or former recipients of rehabilitation services, their representatives, providers of services, employers and others active in the field of rehabilitation.

The Massachusetts Rehabilitation Commission has designed a Program in Consumer Involvement which makes a special effort to form cooperative relationships with those individuals who are known as consumers, or recipients, of services. Issues of concern for individuals with disabilities may be addressed so that the overall environment surrounding disabled citizens is improved. Ultimately, an atmosphere of mutual advocacy will further the cause of those served while it improves the capacity of the Commission to comply with its charge and carry out its mission.

Definitions

As stated above, "consumers" are a sub-group of those whose input is to be considered. Specifically, a consumer is:

1. an individual with a mental or physical disability; or

2. an immediate family member (i.e., parent, guardian, spouse or sibling) of an individual with a disability.

A "consumer representative" is an individual who is elected or appointed by a consumer group to act as a spokesperson for that group and is held accountable by that constituency.

A "provider of services" is one who is employed to assist individuals with disabilities to benefit from employment, education, transportation, housing, public assistance, etc., as needed and/or deemed appropriate.

"Involvement" can be any activity from an individual consumer's input on their Rehabilitation and/or Independent Living Plan to policy development by participation on advisory councils and/or task forces. Such involvement may have an impact on an individual, the agency, or the entire disability community.

HISTORICAL CONTEXT

The MRC Consumer Involvement Program began over 14 years ago in a management environment condusive to the premise that consumers of Vocational Rehabilitation Services had a uniquely original and important point of view on how those services were provided. State law had mandated the Commissioner to regularly convene the Statewide Advisory Council (SAC) consisting of 14 voting members appointed by the Governor. The Commissioner, over time, has included an effective mix of representatives of the provider, business, and consumer communities on this Council.

During the late 1970's, the Commission contracted with Tufts-New England Research and Training Center to build more models of consumer involvement. As a result, Area and Regional Offices in the Vocational Rehabilitation Division developed advisory councils to promote attention to local disability issues of concern as well as to forward more general recommendations to the Statewide Advisory Council. Another model developed by this contract became known as the Individual Policy Consultation (IPC).

The early 1980's marked a major crisis in the lives of people on Social Security Benefits. Critical changes in the eligibility regulations made it impossible for many to remain on the rolls. Consumers demanded a greater degree of involvement. This led to the beginning of the Disability Determination Services (DDS) Division Advisory Committee.

As the 1980's continued so did the expansion of the Independent Living Division. The Independent Living Advisory Council, mandated by federal law, now meets to provide input to the Independent Living Divisions of the Massachusetts Rehabilitation Commission, the Massachusetts Commission for the Blind, and the Massachusetts Commission for the Deaf and Hard of Hearing. This Council maintains a membership of at least 51% parents or consumers of Independent Living Services.

PROGRAMMATIC DEVELOPMENT

Many of the concepts and models which built the Consumer Involvement Program at MRC originated out of the Tufts-New England Research and Training Contract, the 1973 "Rehabilitation Act," and the spirit of good community organizing and advocacy on the part of and by people with disabilities.

Unlike any other social service law at the time, the Rehabilitation Act of 1973 deliberately made room for clients/consumers to take an active role in the development of their plan of services. The Individual Written Rehabilitation Plan, known as the IWRP, supports the right of the client/consumer to agree to services planned with a recognized professional counselor in the field. If an agreement can not be reached, an individual with a disability may appeal the decision to a higher authority.

These provisions, with the support of federal law, remain the first steps to the birth of consumer involvement.

The Advisory Council Network grew out of perceived needs for the policy making levels of the Commission to be in closer touch with the ideas and recommendations of the client/consumer advocates. Recognizing MRC as one in a group of members in a varied community of service providers, as well as employers; the Commission felt more comfortable in reaching out to its "publics" for their recommendations in its improvement of policies and practices. Locally based Area Office Councils could then justify taking an advocacy position in the community to press for services related to people who were severely disabled to be better able to access VR services as well as other human services in that community. Barrier removal, transportation, and housing remain as important as employment for some consumers.

Early in the development of models the need was recognized for more than advisory councils. The Individual Policy Consultation (IPC) model grew into a more generalized model, Individual Consumer Consultation (ICC), where consumers could not only be consulted on policy decisions such as review of new regulations and guidelines but could provide valuable information on:

- program development, planning, and evaluation;
- surveys and studies as to client/consumer population on field office accessibility; and
- staff and consumer training on the rehabilitation progress.

From the beginning, this model also recognized the importance of a reasonable reimbursement for consumers' time. The rate was established at $10.00 per hour. It was raised to $12.50 per hour where it remains today. Specific limits were set on this model. Of most importance was that the reimbursement for consultation services could only be made for an assignment that is both time-limited and task oriented.

Shortly after this practice was established, the importance of support services for persons with severe disabilities was recognized. Such services as transportation, personal care, and/or interpreter services were then provided. Support services are also used for regularly scheduled advisory council meetings.

An important third leg in the development of the Consumer Involvement Program has been the network built by consumer advocates for persons with disabilities around the state as well as nationally. The Consumer Involvment Program holds, annually, a conference for the purpose of information-sharing, strategy-setting, and networking. Representatives for the Independent Living Centers and the Massachusetts Coalition of Citizens with Disabilities (MCCD) as well as the Massachusetts Rehabilitation Commission Advisory Councils, take an active part in developing the agenda for this conference.

The Commission plans to continue with such advisory/advocacy associations knowing that a strong, well organized consumer community will ultimately benefit the serivce delivery system for persons with disabilities.

STAFF RESPONSIBILITIES

One full-time professional staff person is responsible to assist the achievement of the program's goals and objectives in each of the three Divisions of the Commission. This has led the Consumer Involvement Program Manager to act in a supportive role in the selection of particular persons who would be:

- appropriate consumer consultants;
- members of advisory councils and committees; and/or
- providers of services in transportation, personal care, or sign language interpretation.

As staff person to the Statewide Advisory Council and the Statewide Independent Living Advisory Council, the Consumer Involvement Program Manager is responsible:

- to assure meeting agendas and minutes are completed on schedule;
- that support services are arranged for ahead of time; and
- that locations of meeting places are prepared in advance.

The Consumer Involvement Program Manager must also maintain a general understanding of and awareness to other agencies and organizations which are in the process of evolving disability policy statewide, such as:

- Massachusetts Department of Mental Health (DMH);
- Massachusetts Developmental Disabilities Council (MDDC);
- Massachusetts Office of Disability (MOD);
- M-POWER;
- Boston Commission on Disabilities (BCD);
- Alliance for the Mentally Ill (AMI); and others as the need arises.

The Consumer Involvement Program Managers are also responsible for the administration of contracts with specific relation to consumer interests. The Massachusetts Coalition for Citizens with Disabilities (MCCD) is contracted to hold the annual Consumer Conference for about 125 attendees from around the state. The Information Center for Individuals with Disabilities (ICID) provides a wealth of up-to-date information for consumers statewide as well as throughout the Northeast Region of the county. Boston Self Help Center (BSHC) provides client/consumers of the Commission Vocational Rehabilitation Services with unique experiences in peer counseling and peer counseling training in the Greater Boston area.

PLAN FOR CONSUMER INVOLVEMENT PROGRAM

The goals and objectives as stated in the Commission's "Five Year Plan" from 1991 to 1995 are as follows:

Goal: TO CONTINUE TO MAINTAIN AND EXPAND THE ROLE OF CONSUMERS AND FAMILY MEMBERS IN POLICY AND PROGRAM DEVELOPMENT WITHIN ALL THE DIVISIONS OF THE COMMISSION.

Objectives:

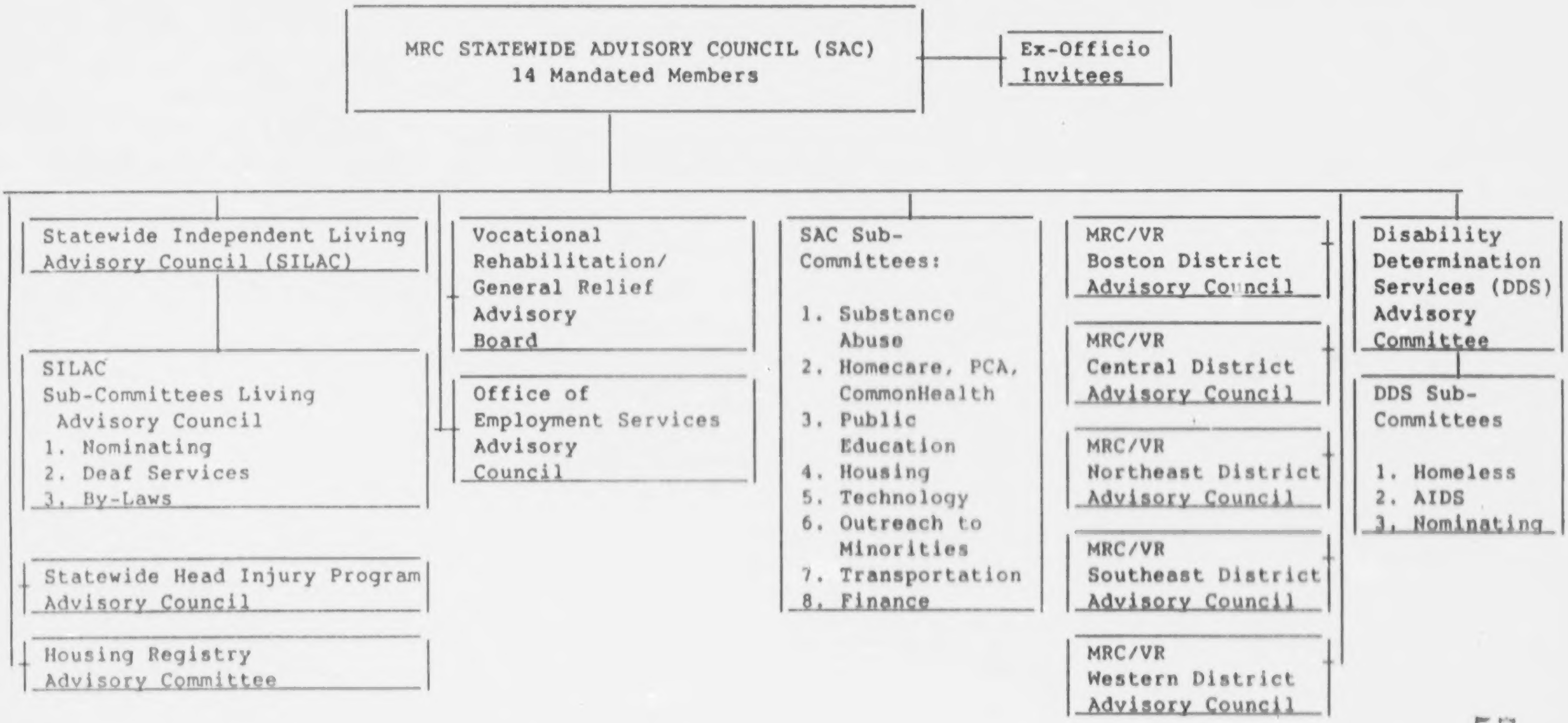
1. To continue to outreach to persons with disabilities who are of ethnic or linguistic minority populations through direct means or by consultation with other State and/or local, public and private agencies.
2. To continue to support and increase the number and frequency of requests for individual consumer consultants.
3. To make certain that consumers are informed of the oportunities to serve in an advisory capacity in each division of the Commission.
4. To continue contact with local and national consumer disability organizations and coalitions to support the growth of a network of consumer service as well as advocacy resources.
5. To assist in the development of consumer advisory and advocacy models supportive of disability civil rights issues on the state and national levels.
6. To act as staff to the Statewide and Independent Living Advisory Councils.
7. To update this Program Statement and Plan annually.

CONCLUSION

The practice of involving consumers remains alive and thriving throughout the Commission. Over time, it has grown in its use from a new and challenging practice to a wise management, marketing, consultation tool. As we look to the "downsizing" of budgets, we will continue to look to consumers for advice at a reasonable cost. What used to be an innovation has become today's common practice.

APPENDIX A

MASSACHUSETTS REHABILITATION COMMISSION
ADVISORY COUNCIL NETWORK



MRC STATEWIDE ADVISORY COUNCIL (SAC)
14 Mandated Members

Ex-Officio
Invitees

Statewide Independent Living
Advisory Council (SILAC)

SILAC
Sub-Committees Living
Advisory Council
1. Nominating
2. Deaf Services
3. By-Laws

Statewide Head Injury Program
Advisory Council

Housing Registry
Advisory Committee

Vocational
Rehabilitation/
General Relief
Advisory
Board

Office of
Employment Services
Advisory
Council

SAC Sub-
Committees:

1. Substance Abuse
2. Homecare, PCA, CommonHealth
3. Public Education
4. Housing
5. Technology
6. Outreach to Minorities
7. Transportation
8. Finance

MRC/VR
Boston District
Advisory Council

MRC/VR
Central District
Advisory Council

MRC/VR
Northeast District
Advisory Council

MRC/VR
Southeast District
Advisory Council

MRC/VR
Western District
Advisory Council

Disability
Determination
Services (DDS)
Advisory
Committee

DDS Sub-
Committees

1. Homeless
2. AIDS
3. Nominating

APPENDIX B

STATEWIDE HEAD INJURY PROGRAM (SHIP)

The purpose of the Advisory Council is to provide input and guidance to SHIP on topics related to program development; consumer satisfaction and quality of service issues; public policy initiatives; budget development and expenditures; interagency cooperation and coordination efforts; prevention initiatives; and overall service delivery issues. Council meetings are held quarterly and subcommittees meet more frequently as needed to address specific short-term agendas identified by the membership.

The Council membership consists of consumers, families and professionals. The Massachusetts Head Injury Association's Executive Director sits on the council as well. People have been nominated from across the state in order to insure geographic representation. There are presently 22 members statewide. The distribution is as follows:

Consumers - 14%
Professionals - 18%
Families - 68%

Geographic Representation

West - 14%
Central - 14%
Northeast - 19%
Boston - 24%
Southeast - 29%

A consumer member of the SHIP Advisory Council is an appointed representative to the Massachusetts Rehabilitation Commission's Statewide Advisory Council.

APPENDIX C/SAMPLE AGREEMENT

NORTHEAST DISTRICT CONSUMER ADVISORY COUNCIL BY-LAWS

Article I. Name and Purpose

Section 1. The name of this group shall be the Northeast District Consumer Advisory Council.

Section 2. To work with MRC and appropriate agencies/ organizations and others to ensure effective and community/responsive vocational rehabilitation services, by advising management on all matters the Council deems appropriate and necessary.

Article II. Qualification for Membership

Section 1. The field of membership of this Council will be persons with disabilities and/or their representatives.

Section 2. Nomination for appointment to the Council must be in writing and directed to the Northeast Regional Director to be forwarded to the Council.

Article III. Meeting of Members of the Council

Section 1. Regular meetings of the Council shall be held once a month at such time and place as the Council shall determine and announce in the notice thereof.

Section 2. At least seven (7) days before the date of any meeting of the Council, the secretary shall cause written notice thereof to be provided to each member.

Section 3. Special meetings of the Council may be called by the Chairperson or designee as requested at the same location as regular meetings. The notice of such special meetings shall be given as provided in Section 2 of this Article.

Section 4. A Quorum shall consist of one-half the voting members or their authorized substitutes.

Section 5. Minutes of the preceding meeting shall be discussed, revised, and adopted at each meeting.

Section 6. Permanent or ad hoc committees may be established by the Council.

Section 7. Except for changes of by-laws, all matters shall be decided by a majority vote of the members present and authorized to vote.

Article IV. Elections

Section 1. At any election of official(s) a quorum of voting members must be present or a written proxy submitted which will be entered into the record.

Section 2. Officers must be nominated by a Council member.

Section 3. The voting for officers shall be conducted by ballot.

Section 4. Proxy voting is permitted given due cause.

Article V. Officers

Section 1. The officers of the Council shall be the Chairperson, Vice-Chairperson both of whom will be elected by Council members.

Section 2. The Chairperson shall preside at all meetings of the Council. The Chairperson shall perform such other duties as pertains to this office.

Section 3. The Vice-Chairperson shall have and exercise all the powers, authority and duties in the absence of the Chairperson.

Section 4. The secretary shall prepare a brief overview of all the meetings of the Council within fourteen (14) working days after respective meetings. A copy of the minutes of every meeting shall be maintained by the Chairperson.

Section 5. Elected offices will be for a one year term not to exceed two consecutive terms.

Article VI. Council Members

Section 1. Council members shall consist of at least 9 voting members with a maximum of 15.

Section 2. Substitutes for voting members are allowed. Substitutes may not vote except by written proxy.

Section 3. If a member fails to attend regular meetings for three consecutive times without proper notification and good cause or otherwise fails to perform his/her duties, his/her chair may be declared vacant by the Council and the vacancy filled after giving due notice in writing to the Council member in question.

Article VII. Amendments of By-Laws

Section 1. Amendments of these by-laws must be adoted by the affirmative vote of two-thirds of the authorized number of voting members of the Council.

APPENDIX D

CONSUMER INVOLVEMENT FY 1991 BUDGET

Services		
Interpreters	$ 8,000	
Personal Care Attendants and Travel	$ 13,000	
Individual Consumer Consultants (ICC)	$ 18,000	
Conference	$ 2,000	
SUB-TOTAL	$ 41,000	
CONTRACTS		
Boston Self Help Center (BSHC)	$ 20,000	
Information Center for Individuals with Disabilities (ICID)	$ 98,000	
Massachusetts Coalition for Citizens with Disabilities (MCCD)	$ 35,000	
SUB-TOTAL	$153,000	
Total Consumer Involvement		$194,000

Resource B

Michigan Association of Multi-Cultural Rehabilitation Concerns

Michigan Rehabilitation Association Minority Task Force

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Michigan Association of Multi-Cultural Rehabilitation Concerns
Michigan Rehabilitation Association Minority Task Force
1989-1994

The Michigan Rehabilitation Association and Michigan Association of Multi-Cultural Rehabilitation Concerns approved and funded the Michigan Minority Issues Task Force (1988-1995). The charge to the task force was to gather information on the perceptions of minorities regarding rehabilitation service providers, use the information to develop training for service providers, build capacity to work effectively with people from different cultures, and to identify resources that are culturally appropriate.

Major and Statewide Activities

- The Minority Issues Task Force was instrumental in establishing a multi-cultural track as an integral part of the yearly state rehabilitation conference. The Minority Issues Task Force also developed and distributed a *Minority Resources Directory*. The directory included agencies, programs, and private practitioners who have qualified staff to meet the unique needs of people with disabilities from minority populations.

- State-wide training on multi-cultural issues was provided. In addition, a focus group researched and authored an article entitled "Rehabilitation Service Provider: A Minority Perspective", which was published in the Summer, 1995, edition of the *Journal of Applied Rehabilitation Counseling*.

- Michigan Rehabilitation Services included in its state plan multi-cultural diversity objectives.

- A pilot in-service training on multi-cultural issues was field tested, Summer, 1995. Modifications to the training program are being made, and training for all rehabilitation staff will be provided on a statewide basis.

- A Consumer Advisory Committee was developed to provide service delivery recommendations to the "no wrong door" Workforce Development Board. The charge to the group was to develop a plan that would insure that rehabilitation services, funds, and qualified staff were appropriately designated and available to address the unique employment service needs of people with disabilities. The Advisory Council includes consumers, rehabilitation providers, special education, advocates, workforce development members, rehabilitation services, and employers. This collaborative effort will serve to influence policy making decisions and build advocacy skills needed to successfully broker change within the political environment.

- In Kalamazoo, a Consumer Advisory Group was convened to provide continuous input to the local district office on effective service delivery strategies that would result in positive employment outcomes for consumers.

- In Detroit, Pontiac, and Flint, the Michigan Jobs Commission/Rehabilitation Services networked with African-American churches to provide information on eligibility and scope of services available to people with disabilities. The objective was to increase access to services as cited in the Rehabilitation Act Amendments 1992.

- The Michigan Jobs Commission/Michigan Rehabilitation Services created a Medicaid Health Insurance disincentive work group. A statewide conference consisting of consumers, rehabilitation organizations, advocates, and service providers convened for the purpose of bringing together key partners to discuss and plan the future direction of the state rehabilitation program. This was a kick-off event to stimulate building community alliances with partners throughout the state. At this meeting, consumers expressed concerns about current medical disincentives that people with disabilities who want to work must resolve i.e., employers unwilling or unable to cover pre-existing conditions of new employees. Such policies negatively impact on the ability to enter the labor market. This issue was a predominant concern expressed by consumers during the meeting. Michigan Rehabilitation Services responded to this consumer issue and quickly developed a health insurance disincentive work group. The charge to the group was to collaborate with the Department of Social Services, Mental Health and the Michigan Advisory Council to develop a strategic proposal to address the Medicaid disincentives in the state of Michigan.

- The Michigan Career and Technical Institute (MCTI) created a Student Advisory Council. MCTI is a state run vocational school that provides state of the art vocational training and job placement services. MCTI is unique in the sense that the school has qualified staff and facilities that meet the unique employment needs of individuals with disabilities. This vocational school has strong partnership/relationships with local employers who hire a high number of graduates. Because of the Student Advisory Council, the school has positively responded to issues raised by the student minority population on issues that impact on a student's ability to successfully complete training, e.g., differential interpretation and application of policies and procedures in relationship to minorities, lack of funding, and attitude of the service provider.

- The Michigan Jobs Commission/Rehabilitation Services responded to the Hispanic community. A Hispanic counselor was designated to work with this population. Use of culturally appropriate interaction and counseling techniques were key to building trust in the system and enhancing successful employment outcomes for consumers.

- Arab Americans were in need of assistance to adjust to the American culture, and facilitate access to employment and education. A human service programs was developed to meet the special needs of this cultural group. The program, called Access, responded to customers needs and developed a service delivery model that was culturally effective and sensitive.

Task Force Objectives

The Minority Issues Task Force also developed the following twenty objectives:

1. To facilitate a process in which member organizations conduct self-appraisal, assessing effectiveness with minorities they currently serve, setting goals for increasing the numbers of minorities served, and the effectiveness of services.

2. To work with universities and certification programs to ensure recruitment of minority students in the fields of psychology and vocational rehabilitation. In addition, secure federal funding to underwrite or facilitate training in cross-cultural issues for psychologists and vocational rehabilitation counselors.

3. To work more cooperatively with minority recruitment programs in state and federal civil service to increase the numbers of minorities entering human service professions and achieving promotion within those professions.

4. Managers of rehabilitation agencies must develop resource lists of interpreters, psychologists, social workers, physicians, and other service delivery professionals who have demonstrated effectiveness in serving members of minority cultures as well as listing those who are able to speak clients' primary language.

5. Advertisements and public service announcements should not only be in languages other than English, but should also represent culture-appropriate models.

6. Promote the development of university-level courses on culturally appropriate counseling and vocational guidance techniques.

7. Work with the Commission on Rehabilitation Counselor Certification to ensure the inclusion of cross-cultural competencies in the testing process and a requirement for participation in cross-cultural counseling training programs in meeting the continuing education requirement.

8. Promote the development of career guidance model and materials for high school students that is appropriate to various cultures.

9. Promote the provision of culturally appropriate rehabilitation services to minority students with disabilities via the State Department of Education, intermediate school districts and local school districts.

10. Aggressively advocate for expanded work incentive for Public Assistance recipients--including full disclosure of these incentives to rehabilitation professionals and to consumers.

11. Work with legislators to initiate incentives aimed at increasing the employment rate of minority individuals with disabilities.

12. Implement a plan for outreach to minority professionals to join the Michigan Rehabilitation Association to ensure a balanced vision of the organization's mission and activities.

13. All Board Members of MRA should be expected to participate in training on culturally appropriate counseling techniques, service delivery, and issues related to management of services to minorities. In so doing, members support the effort, gain information, and serve as role models.

14. To support and underwrite a series of conferences on cross-cultural service issues.

15. As purchasers of services, member organizations should promote the provision of training in culturally appropriate service delivery by vendors.

16. Secure federal and National Rehabilitation Association funding to assure ongoing training in cross-cultural issues.

17. Secure funding for a handbook and visual media on cross-cultural service delivery issues.

18. Work with the Spinal Cord and Brain Injury Registry to develop models for the delivery of culturally appropriate services.

19. To secure funding for and initiate a research and demonstration project aimed at targeting an underserved segment of the minority population (e.g., vocational counseling, planning, and employment services for African-American males with spinal cord injuries.

20. To endorse and promote action by member organizations on the recommendations of the Task Force.

Participation of Individuals with Disabilities in Shaping the Direction of State Rehabilitation Programs

Resources

Alston, R. J., & Mngadi, S. (1992, Summer). The interaction between disability status and the African American experience: Implications for rehabilitation counseling. *Journal of Applied Rehabilitation Counseling, 23*(2), 12-16.

This article addresses the double bias of being African American and disabled. Special focus is on the similarities in stigmas experienced by people with disabilities and members of the African American community and how the interaction between minority race status and disability status effects the delivery of rehabilitation services to this population. The client-centered approach is described and suggested as a theoretical orientation to be adopted by rehabilitation practitioners to lessen the impact of a double stigma on this population."

Jenkins, A. E. (1989, September). *Delivery of rehabilitation services to blacks who are disabled.* Paper presented at the Annual Meeting of the National Rehabilitation Association, Orlando, FL.

An paper which looks at the African American living with a disability, perceptions of family, school, human services employment, and feelings about self.

National Council on Disability. (April, 1993). *Meeting the unique needs of minorities with disabilities.* Report to the President and the Congress, Washington, DC.

Addresses systemic inequities in the delivery of rehabilitation services to minorities. Recommendations to correct the inequities are provided..

Sheppard, C., Bunton, J., Menifee, S., & Rocha, G. (1995, Summer). Rehabilitation Service Providers: A minority perspective. *Journal of Applied Rehabilitation Counseling,* 26(2), 36-40.

Findings of the 1993 Michigan Multi-Cultural Issues Task Force Customer Focus Group Study. The focus of the project was aimed at "exploring consumer perceptions regarding the inter-play among disability, race, and the provision of rehabilitation services." The project was motivated by the desire to learn first-hand about the perceptions and attitudes of minority group members who have disabilities and to develop recommendations that could be applied by rehabilitation service providers.

Michigan Minority Resource Directory.

Contact Gloria Rocha, Co-Chair of the Michigan Rehabilitation Association Multi-Cultural Task Force, 1200 Sixth St., Suite 1601, Detroit, MI 48226, (313) 256-2407.

What's Wrong With This Picture?

An interactive video and study guide depicting culturally appropriate counseling techniques. Specific emphasis on African-American, Hispanic, Native American, Asian-American and Arab-American cultures. Produced by the Michigan Rehabilitation Association Multi-Cultural Task Force, co-sponsored by RCEP, Michigan Council on Multi-Cultural Rehabilitation Concerns and Michigan Rehabilitation Services Jobs Commission. Contact: Sylvia Menifee, Michigan Jobs Commission, Rehabilitation Services, 250 Elizabeth Lake Road., Suite 190, Pontiac, MI 48341, (810) 338-0444.

Resource C

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Resource D

IMPACT
Feature Issue on Leadership by Persons with Disabilities

Institute on Community Integration
University of Minnesota

IMPACT

**INSTITUTE ON
COMMUNITY INTEGRATION**
COLLEGE OF EDUCATION
AND HUMAN DEVELOPMENT

UNIVERSITY OF MINNESOTA

Feature Issue on Leadership by Persons with Disabilities **Volume 8 (3) Summer 1995**

For 25 years, Barb Eaton lived in a state institution. Today, she is working with other self-advocates to tell the stories and preserve the memory of all who've lived in Minnesota institutions. See story below and on page 24.

Making Things Better: Barb's Story

by Walter Rupp

Barb Eaton doesn't consider herself a leader. "I'm a doer. I just like to get things done and make things better." In the late 1980s, Barb worked tirelessly to cut through bureaucratic red tape and gather information about the 25 years she lived in a Minnesota state institution. With the help of others, her efforts resulted in a video documentary called *The Lost Years*, which chronicles her life before, during, and after living in the state institution. It is an incredible story of Barb's personal growth and her relationship with her family and community. Barb says she told her story for personal reasons. "My work to tell my story in *The Lost Years* video was a healing process for me. It helped me understand myself better and to get closer to my family." Barb often talks about how the process of telling her story led to a great many new friends and pushed her to do things she had never done before. "I challenged myself to do things I didn't know I could do and I proved to myself and others that I could do it."

Barb has been involved with self-advocacy groups in the past, but only marginally. She says that she has often found self-advocacy meetings frustrating because things often didn't seem to get done. But recently, Barb got involved with a group of self-advocates and others working to place names on the numbered or unmarked graves of Minnesotans buried in state institution cemeteries and to tell the stories of people who have lived in Minnesota's state institutions. The project is

Eaton, continued on page 27

From the Editors

Most persons do not view themselves as leaders. This is in part because of the images of a "leader" that are offered us. Leaders, for example, are often viewed as charismatic individuals who inspire others to action through fiery speeches. Leaders are also often thought of as unusually attractive, intelligent, powerful, talented, and/or prosperous. Still others think of leaders as martyrs who sacrifice all for a cause. While there are leaders who have these traits, we believe that there are other ways of looking at leadership that make it an option for all persons, not just the exceptional few.

Among those who benefit from a re-examination of the concept of leadership are persons with developmental disabilities. Many people have assumed that leadership and disability are incompatible. Yet, in spite of exclusionary definitions of leadership, individuals with developmental disabilities have in fact been filling many leadership roles, especially in the disability rights movement. They have, intentionally and unintentionally, debunked the myth that people with disabilities cannot lead.

In this *IMPACT* are the stories of some of those individuals. Readers will also find models for organizations, schools, businesses, and agencies to follow in embracing a more inclusive vision of leadership, and creating opportunities for more people with disabilities to develop and exercise their capacity for leading.

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A publication of the Institute on Community Integration (UAP) and the Research and Training Center on Residential Services and Community Living, College of Education and Human Development, University of Minnesota. Dedicated to improving community services and social supports for persons with disabilities and their families.

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Leadership: Where We've Been, Where We Are, Where We're Going

by Hank Bersani, Jr.

What does it take to be a leader? What makes a movement? Who are the present and former leaders in the developmental disabilities movement? What will come next? In the past, these were relatively straightforward questions with fairly clear, direct answers. Today, however, the responses are more complex because many more voices are being heard, most significantly the formerly silenced voices of people with disabilities. Leadership in the disabilities movement has emerged where we never expected it a few decades ago: from individuals with developmental disabilities. They represent the latest of three stages, or "waves" as I call them, in the evolution of the movement to date.

■ The First Wave: Professionals

Not long ago, the field of developmental disabilities was more of a professional discipline than a rights movement, although many in the discipline were in fact interested in the rights of people with developmental disabilities. Among these professionals, leaders were people with academic credentials who held positions in the related fields of medicine, psychology, education, and special education. From as early as 1850 to as recently as 1950, the list of leaders in the field that we now call *developmental disability* were famous professionals who had developed test procedures, reached clinical insights, and started new programs. Books on what we called *mental retardation* featured the "early leaders" such as Itard, and Seguin and Howe, physicians in the 1800s.

Leaders in the field often functioned within organizations. Until the 1950s, the oldest and largest organization in the field was the American Association on Mental Deficiency (AAMD). For over 100 years, AAMD was an association of professionals, by professionals, for professionals, and the assumptions of the time were clear: Professionals know what is best, people with disabilities are defined by their disabilities (mental deficiency), and skilled researchers and scientists will lead the way to better services, therapy, and reduced disability. I have called this stage of leadership development "The First Wave."

In those days, at the height of The First Wave, professionals, as leaders, defined the issues and created the new discipline of developmental disability separate from the fields of medicine, psychology, and education. They made decisions on their own or in consultation with each other. The activities of these leaders included forming state and national organizations, convening national conferences, publishing research articles and books on disability, issuing position statements, and consulting to programs locally, nationally, and even internationally.

During The First Wave, people with developmental disabilities were often seen as less than human. To most professionals, they were "subjects" in experiments and the objects of studies. In the United States at this time there was a growing emphasis on the role of science in our lives. Therefore, the goal of the disabilities field was to apply science to achieve better understanding of causes and possible cures of the "deficiency." Consequently, people with "mental deficiency" were viewed as having nothing to contribute to the field beyond their role as subjects of research. In addition, as the science around disabilities evolved, it focused increasingly on prevention – immunizations, testing for problems such as PKU, and so forth. In the context of a focus on the science of prevention, there was little use for the people who represented failures of prevention efforts.

■ The Second Wave: Parents

In the late 1940s and early 1950s, there was a dramatic development: the Parents Movement. After World War II, the United States experienced a new prosperity. People had more leisure time and more income. This meant that they were able to turn their attention to issues other than economic survival. Concurrently, the baby boom was taking place, which meant that not only were more babies being born, but also more babies were born with developmental disabilities. As a result of this combination of factors, parents of children with disabilities, especially mental retardation and cerebral palsy, began to form their own support and advocacy groups. This was "The Second Wave."

At first, the goal of these organizations was simply for parents of children with disabilities to support one another. Later, as the organizations matured, parents also began to advocate for themselves, their children, and each other. In order to win the respect of the professionals in the field, they became more organized, although at the time no one called it a "movement." As parents of children with disabilities sought each other out, they formed local and state organizations, and a national organization that was at first known as the National Association for Retarded Children (NARC).

The Parents Movement had a profound effect on the developmental disability field. Parents acknowledged that there was a role for professional expertise, but they pointed out that they knew their family members better than any professional ever would. As parents, they had a lot to say about their family members, especially their young children. They demanded that parents be included when professionals met to discuss the needs of children with disabilities.

Many parents joined the professional organizations, including AAMD. At one point there was a suggestion to make the emerging parent organization, NARC, a part of AAMD. The president of AAMR, Mildred Thompson, had the good sense to say that the best way that AAMD could support the Parents Movement was to assist them in developing their own organization. At the height of The Second Wave, NARC's membership far exceeded that of AAMD. Several other parent organizations formed as well. Parents had established themselves as leaders. They joined professional organizations, formed their own organizations, established newsletters and journals focusing on parent issues, published in professional texts and journals, shaped the language of the field, and redirected the emphasis at conferences.

■ The Third Wave: Self-Advocates

In the early 1970s, something remarkable happened in the field of developmental disabilities. The 1950s and 1960s had been a time of new advocacy groups forming on a range of issues across the country. From Ralph Nader's consumer advocacy, to the civil rights movement, to the women's movement people were claiming greater power, control, rights, and freedom for themselves and others. People with developmental disabilities, the same people whom the professionals and even the parents had called "clients" and "the retarded", also began to organize with the help of staff and other allies. What emerged as "The Third Wave" of the developmental disabilities movement has become known as the Self-Advocacy Movement.

Self-advocates have organized partly in reaction to the attitudes promoted by professionals and parents, and also in part to copy those groups' methods as effective approaches to advocacy. In the past 25 years, self-advocates have formed their own organizations at local, state, and national levels, so that today there are over 600 self-advocacy groups across the country. Self-advocates have organized conferences to discuss issues that are most important to them, joined the long-established professional and parent organizations such as AAMD and the Arc, published their own newsletters, published articles in journals and newsletters of parent and professional organizations, given major addresses at professional and parent conferences, published chapters in books, and changed the language of the field to "people-first." A major milestone in this Third Wave has been the establishment of the national organization, Self Advocates Becoming Empowered. To the leaders in the movement, the formation of the group was a major step in achieving a national presence.

Many self-advocates have identified their own significant indicators of success. As a long-time supporter and observer, several individuals and events stand out for me:

- Valerie Schaaf was one of the founders of People First International 25 years ago. She went from living in an institution to being a national leader in the Self-Advocacy Movement, and is generally credited with originating the phrase, "see people with disabilities as people first."
- Barbara Goode, a leader of the Self-Advocacy Movement in Canada and internationally, recently was selected to give an address to the General Assembly of the United Nations.
- Michael Kennedy, a self-advocacy leader from New York state, testified before the U.S. Senate on his years growing up in an institution. His leadership has inspired many others to become self-advocates.
- The People First group in Tennessee made history by being the first self-advocacy group to bring a lawsuit against the state to close an institution.
- In Colorado, self-advocates, including Debbie Allen, lead the fight to have people with disabilities included on the boards of directors of service agencies.

For most self-advocates (and for me) the greatest measure of success is how they have affected the rest of us, the professionals and parents. They have changed our organizations, the names of our organizations, our attitudes, our language, our practices, and have caused us to redefine our issues. They have brought us slogans such as "Nothing about me without me." And they have made us nervous.

Making people nervous is an indicator of success. If a would-be social movement has only a few members and no power, they do not make us nervous. We become concerned when the group becomes big enough and organized enough to be an effective movement. That causes a reaction from those who want things to remain unchanged. We wonder, "Will they go too far? Can they go too far? What will be our role if they become the leaders? What part of my expertise is still useful or wanted?" When The Second Wave emerged, professionals were reluctant to give up any of their power to parents. Today, many parents and parent organizations, in addition to professionals, are also reluctant to give up their power and influence to self-advocates. But, there is no changing the inevitable: We cannot and should not discuss developmental disabilities without the participation of the individuals with disabilities themselves. In this Third Wave, the leaders in the developmental disabilities movement are the self-advocates. And the biggest sign of their success as leaders is that they make the rest of us – professionals and parents – nervous.

Hank Bersani, Jr., is Director of Special Education with the Oregon Health Sciences University, Portland. He may be reached at (503) 494-3696. Many of the concepts presented here are discussed in a new book by Gunnar Dybwad and Hank Bersani entitled New Voices: Self-Advocacy by Persons with Disabilities *published by Brookline Books.*

Leadership by Persons with Disabilities: Perceptions, Needs, and Opportunities

by Brian Abery and Michael N. Sharpe

If one defines leadership in the manner in which it is typically viewed in our society – such as Martin Luther King's ability to inspire a great social movement through the use of extraordinary oratory skills – then it is a foregone conclusion that there will always be a shortage of effective leaders. This is not, however, the only manner in which one can view leadership. A broader perspective is that *all* persons inherently have the potential to lead.

> ... although each person may use a unique leadership "style" and be faced with a different set of leadership challenges, everyone has the potential to learn and apply leadership skills.

The belief that the capacity for leadership is present within all individuals is based upon two fundamental assumptions. The first focuses upon the idea that although each person may use a unique leadership "style" and be faced with a different set of leadership challenges, *everyone* has the potential to learn and apply leadership skills. Some persons may lead through using their organizational abilities. The leadership of others may emerge as a result of their capacity to assist groups in reaching consensus. Still others may have the gift of oral or written persuasion. Regardless of the specific skills they employ, each of these persons is carrying out a leadership function.

The second assumption underlying the belief that all persons have the potential to effectively lead transcends the typical notion of leadership as based upon the efforts of a single individual; it redefines the construct from an empowerment perspective. Viewed from this position, an effective leader is not necessarily a person who possesses all of the skills and capacities necessary to facilitate a group reaching its goals, but rather is an individual who effectively empowers others to use the capacities they possess to their fullest potential in an effort to promote individual and group goals. Given this broader perspective, leadership may be thought of as a collection of interpersonal skills and values that enable an individual to facilitate group achievement of the following: (a) developing and reaching consensus with respect to a vision, mission, and set of goals; (b) deciding on a course of action; (c) working in an effective manner to reach its goals; and (d) enhancing the self-actualization, empowerment, and self-determination of its members. This definition is quite different from traditional perspectives on leadership.

Viewed through this lens, effective leaders are not necessarily people who have a vision and, through great skills of persuasion, convince others to follow them. Rather, leaders are persons who are effective at facilitating groups of individuals collaboratively deciding what they want to do and how this can best be accomplished. It is unlikely that many persons will possess all of the skills and characteristics necessary to facilitate these tasks. This does not mean that such individuals are not good leaders. Effective leaders are aware of their capacities as well as their limitations, and are willing and able to drawn upon leadership abilities of other group members to help achieve common goals.

In addition to the belief that leadership can be expressed in many different ways, it is also proposed that opportunities for leadership exist in everyday life and that it is only a matter of degree and one's own personal circumstances that determine the extent to which leadership skills are applied. Parents, for example, exhibit leadership when they help other family members decide upon a course of action. Children display leadership when they suggest modification of the rules of a game so that all present have the opportunity to play. These would not necessarily be viewed as instances of leadership using traditional definitions of the construct. Upon close examination, however, it can be seen that, in each of the above examples, actions were taken that facilitated a group of individuals achieving a goal.

The importance of identifying and facilitating the distinctive qualities of leadership is neither purely academic nor insignificant for persons with disabilities. Many of the significant changes within educational and social service delivery systems that have enhanced the quality of life of persons with disabilities have been initiated by such individuals themselves. Whether at the local, state, or federal level, the work of individuals with disabilities functioning in leadership capacities has been critical to the passage and enforcement of disability rights legislation, changes in the manner in which residential services are provided, and increased opportunities for meaningful participation in the workforce. The Americans with Disabilities Act and the Individuals with Disabilities Education Act, for example, would in all likelihood have never been passed without the leadership skills of persons within the disability community. The formation and growth of consumer advocacy groups would have been impossible in the absence of the leadership provided by many self-advocates. It was persons with disabilities who served as the catalysts behind deinstitutionalization and the creation of less restrictive community residential and employment programs.

There exists today a critical need for skilled, informed persons with disabilities to serve as advocates for other individuals with disabilities and to stimulate systems change. Unfortunately, there is only a limited pool of persons with disabilities who have had the opportunity to fully develop their leadership skills. Many of these persons have spent countless hours organizing within the community, testifying in legislative bodies, and educating the general public about disability-related issues. Presently, however, there are simply not enough of these individuals to take on all leadership functions. As a result, discussion and action related to issues needing attention must often be postponed.

The efforts of individuals with disabilities who have served as leaders have contributed enormously to enhancements in the quality of services available to this group, as well as to their increased inclusion within the community. Because leadership is typically considered to be an attribute possessed primarily by "the gifted and talented," however, persons with disabilities have, for the most part, been excluded from participation in leadership development programs and have had few opportunities to assume positions of leadership within communities. Similar to the experiences of persons of color, women, and those from disadvantaged circumstances, members of this diverse group have been viewed as lacking the potential to function effectively as leaders. When persons with disabilities do receive the opportunity to practice and refine their leadership capacities, it is typically within the context of preparing them to function as leaders of "the disabled" rather than within society at large.

Over the past decade, persons with disabilities such as Judith Heumann, T.J. Monroe, Nancy Ward, and the late Ed Roberts have assumed positions of leadership in a variety of organizations serving children and adults with disabilities. The efforts of these individuals have done much, at the societal level, to improve the quality of life experienced by persons with disabilities and to dispel the belief that such individuals are not capable of functioning as effective leaders. The majority of individuals with disabilities who have become effective leaders, however, have done so in spite of, rather than as a result of, the manner in which they were treated within society.

The positive impact of the leadership of persons with disabilities is not limited to a few individuals whose efforts have stimulated change at the societal level. The ongoing efforts of persons with disabilities who do not even consider themselves to be leaders have brought about changes that have resulted in an enhanced quality of daily life for both themselves and others. The experiences of Jim, Susan, and Kevin bear this out. Jim, a 36-year-old man who has spent the majority of his adult life working in a sheltered workshop, recently was successful in convincing those who operate the program to install large fans to make the work environment more comfortable during the summer months. His success was largely due to his persistence, belief in the validity of his cause, and ability to organize all 16 of his coworkers in support of this change. Although the air conditioning that he and his coworkers would prefer has yet to be installed, Jim's efforts have led to a considerably more comfortable work setting for himself and his peers.

Susan is a 45-year-old woman who currently resides in a six-person community residence operated by a respected service provider. Although she has few complaints about her accommodations, Susan recently initiated an effort to pressure her service provider to drop the name "children" from the agency title since the organization currently serves only adults with developmental disabilities. Although this effort may appear trivial to some, to Susan and her peers it represents an attempt to "make sure that the persons who work with us recognize that we are adults just like them."

As one of the first students within his school district to receive his education primarily within inclusive settings, Kevin led by example for a number of years, demonstrating to fellow students, parents, and professionals that persons with developmental disabilities cannot only survive but are able to thrive within general education settings. The leadership this young man exercises, however, goes far beyond his merely serving as a role model. Since his high school years, Kevin has spoken at local, state, and national levels to fellow students, parents of children with disabilities, and professionals about his experiences within inclusive education settings.

Enhancing the quality of life of persons with developmental disabilities is a long-term effort. It is an effort that, if it is to be successful, must receive its direction not from professionals or parents, but from persons with disabilities themselves. The identification of policies and regulations that need to be changed, problems that must be addressed, and programs that are important to develop can be best accomplished through extensive input and leadership on the part of those individuals most affected. Until persons with disabilities are supported to lead and provide direction with respect to these efforts, attempts to achieve the goal of full inclusion within the community will remain less than adequate.

Currently, there are many obstacles to individuals with disabilities assuming leadership roles. Among the most powerful of these barriers are those that are attitudinal in nature. Myths and misconceptions about the capabilities of persons with disabilities remain entrenched within our society, reinforced by a service system that appears more interested in focusing on what individuals cannot do as opposed to their capacities and potential. Attempts to question authority are referred to as "challenging behavior," efforts to stimulate change viewed as irritants, and compliance deemed an acceptable program outcome toward which to aspire. In addition to external attitudinal barriers, many individuals with disabilities do not view themselves as having the capacity to lead, in part because the current system under which they receive services functions to effectively socialize many of them into dependent roles. Until this cycle is broken and persons with disabilities begin to envision

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The Impact of Gender and Race on Leadership by Persons with Disabilities

by Jacquelyn Anderson Bolden

Much has been written about leadership, both formally in the social science and management fields and informally in popular publications. For too long leadership has been conceptualized narrowly as a special form of power and influence. When constructed in this way, many people become exempt from leadership roles because they are not viewed as having the requisite capacities to do the job. In the United States, many individuals – on the basis of their race or ethnicity, gender, and/or disability – also experience restricted access to leadership roles as a result of individual and institutional discrimination. In spite of changes in our social structures, workforce, and legal system, leadership roles continue to be narrowly distributed.

Three themes emerge in the general literature about leadership that are relevant to the discussion of leadership on the part of people with developmental disabilities. The first is that leadership need not be narrowly distributed; leadership possibilities exist across gender, racial, class, and other boundaries. The second theme is that leadership roles are fluid, not static. And the third is that people are not born leaders, but develop leadership skills. These three themes will be explored here in an effort to develop strategies for encouraging leadership that facilitates the self-actualization, empowerment, and self-determination of individuals with disabilities.

■ Who is an Appropriate Leader?

Opportunities to develop the capacity, gain the experience, and obtain the opportunities to lead are influenced by society's perceptions of individual and group appropriateness for leadership roles. Leadership and the male role within American society have traditionally been seen as congruent, while leadership and the female role have often been thought of as incongruent. Several factors are responsible for this. One is that womens' rewards have traditionally not been located in the leadership arena, but in the realm of caring for others. Further, because women are socialized to hold non-leadership roles, societal expectations function to diminish their motivation for leadership. Contemporary options for paid employment have significantly affected role expansion for women, and women leaders are becoming more visible. Assumptions about the *appropriateness* of female leadership, however, are still of central importance to consider in discussions about limits on women's opportunities.

The legacy of exclusion of Native Americans, African Americans, Asian Americans, Latinos and other racial/ethnic groups from participation in mainstream American life continues to have an impact upon opportunities for achieving leadership positions in many organizations and professions. It can be argued that legal and social barriers can be held responsible for the underdevelopment of leadership capacity among individuals in different racial/ethnic groups. Segregation, however, did not preclude the development of leadership skills within racial/ethnic communities. Notable contemporary leaders like Jewel McCabe, Eleanor Holmes, Dorothy Height, Jesse Jackson, and Andrew Young held important and visible leadership positions in African American communities during periods when de jure and de facto segregation precluded their involvement in these roles within mainstream organizations. Today, while formal legal barriers have been lifted, racial discrimination continues and resistance to include racial/ethnic people in mainstream leadership roles persists. Assumptions about their capacity to lead in wider society are the primary stereotypes to be challenged for racial/ethnic people.

The exclusion of persons with disabilities from mainstream society has served to marginalize and limit them, as well. Persons with disabilities are perceived as perpetual children and are therefore not socialized to occupy key roles in society. The focus on what people with disabilities are *unable* to do has significantly affected the perception of what they are *able* to do. Assumptions that limit the possibility of leadership must be addressed if persons with developmental disabilities are to experience role expansion.

The experience of exclusion from leadership roles that are valued by society as a whole is intensified for individuals who are members of more than one excluded population. When considering leadership by persons with disabilities, it is important to recognize that they may not only be dealing with biases – internal and external – based on perceptions about disability, but if they are female and/or members of minority racial/ethnic communities, there are additional biases and barriers to overcome.

■ What Do Leaders Do?

Leadership is contextual. Therefore, what is expected of a leader is dependent upon the setting and the needs of the group. Formal leadership roles typically include solving problems, planning for group action, directing activities, communicating effectively, understanding and developing oneself, accessing resources, understanding financial matters, being creative, managing meetings, and arbitrating. A leader is not someone who possesses leadership traits. Leadership, like any other role behavior, is a function of dynamic interaction between personal attributes and the social system.

Leadership is distributed in varying amounts among group members most able to meet group needs. As needs change, leadership distribution within the group changes.

Leadership skills are acquired through formal and informal processes. The development of competencies for leadership include the opportunity to practice and use knowledge and skills. Organizational and community initiatives have evolved to provide models for the development of leadership competencies among many who have been formerly excluded. Self-advocacy projects, for example, have emerged to teach persons with developmental disabilities strategies for problem-solving, identifying resources, and posing key questions to obtain important information. Preparing an agenda, conducting a meeting, and encouraging group members to work in committees are among other skills taught. The diversity of skills that need to be taught depends largely upon the organization or group in which they will be utilized. Generating a list of what one needs to know or do to be effective in an organization or group is a strategy for delineating which competencies may need to be developed.

While the potential for developing leadership skills exists in settings where women and racial/ethnic persons with disabilities receive services and participate in programs, such individuals are often excluded. One explanation may be institutional discrimination. The maintenance of racial, gender, and ability hierarchies occurs because services and programs for persons with disabilities mirror those in the wider society. These all tend to be hierarchical. Administrators and staff consciously and unconsciously reproduce situations and structures with which they are familiar and comfortable. For example, when white male directors identify leadership opportunities for persons with disabilities, often women and minorities are not initially considered. In instances when women and minorities are selected for leadership opportunities, sufficient supports that would facilitate their success in novel roles may be absent.

Leadership Development: A Case Study

The following case study is provided to illustrate how one African American woman with a disability *was* provided with opportunities to develop leadership skills and was supported until her transition to leadership roles occurred. Deana[*] is a woman with a developmental disability who has been involved in a mutual help and self-advocacy organization. She resides in a group home, but would like to occupy a supervised apartment in the city. Prior to the group home, she had lived most of her life in a large residential facility. When she initially became involved with the self-advocacy organization, she was extremely shy and, because of past experiences with racial discrimination, expressed concern about being the only African American in the group. Over time, she began to feel safe and trusting of fellow members. Consistent attendance and participation in the meetings and social events of the organization formed the basis of her initial steps toward leadership skill acquisition. Taking responsibility for herself was critical to assuming other responsibilities. After attending organizational meetings for more than a year, Deana had developed a network of friends within the group. This network provided support, urged self-acceptance, and encouraged her to attempt more activities. As Deana became more confident, she began to reach out to others as well. Participation in formal leadership within the organization began to evolve with her willingness to take responsibility for reminding others to attend group meetings with phone calls. Later, she selected records for a dance, planned a menu for a picnic, and initiated action to acquire recreational materials for the group. After being involved in the organization for more than five years, she led a group to the state capital to speak to elected officials about legislation.

Deana's story points toward the possibilities of leadership acquisition through the process of building competencies and providing meaningful opportunities to learn new skills and take on new challenges. It also points to the multiple issues that need to be addressed when gender and racial barriers have reinforced the marginalization experiences of disability. Deana's self-esteem issues were complicated by her negative experiences of racial exclusion; her willingness to get involved in the organization was compromised by her distrust of the group. Her hesitancy to try many roles was complicated by her ideas about what women are able to do; she volunteered to do gender-stereotyped tasks (like menu planning) before she was willing to assume responsibilities that were more gender neutral or "male like."

Conclusion

How can service providers and advocacy groups avoid stereotyping individuals with disabilities on the basis of gender and racial/ethnic identity? First, those in positions of responsibility or authority can routinely ask themselves, "Have I given everyone a chance to try a leadership role? If not, why not? Do I limit the kinds of tasks I ask women and minorities to do? Have I encouraged women and minorities who are in new leadership roles, and offered support so that they are more likely to succeed?" Secondly, service providers and advocacy groups can develop strategies to assure that inclusion occurs. A buddy system that pairs a new leader with a more seasoned one is one way to use mentoring to support those new to leadership roles. Formal training opportunities can also be provided, incorporating role playing and situational practice. The possibilities for leadership development are limitless. Creative problem-solving and a desire for change are the primary components required to make it happen for *all* persons with disabilities.

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[*] Pseudonym

Real Leaders Ask Questions, Real Leaders Make People Understand

by Michelle Hoffman

It happened again. Rob, who was promoted last fall from direct care staff to program coordinator, was fired because he couldn't fulfill his role as coordinator. He sure was great at direct care, though. And just the other day, Lisa, who was a case manager and took the job as executive director of an employment agency, resigned because she didn't want the responsibilities of being a director.

Again, we are reminded that leadership is an art. It is something to be learned and nurtured over time. Building and fine-tuning leadership skills is a process for us all. Real leadership does not happen overnight. It does not come with a label or a position. Personal experiences, personal drive, and opportunities to learn and grow as leaders give us the materials needed to build and develop our skills.

> Many members had been placed on boards and committees and were eager to serve. However, members did not feel involved, supported or important to the group process and were therefore stuck in a role without direction.

In the realm of consumer leadership, a surge of leaders has been emerging as a result of the self-advocacy movement. Years of organizing and developing leadership skills have paid-off as the movement produces some of the finest leaders in the disability field. The very people who were once locked out of leadership roles, given meaningless board and committee positions, and often (still) told to "be quiet and let us take care of things" are taking their rightful places as leaders. Through the self-advocacy movement, much discussion, writing, and teaching is occurring regarding consumer leadership. Several state groups, such as People First of Tennessee, People First of Washington, Speaking for Ourselves, and Oklahoma People First have produced materials and training about consumer leadership.

One such training program, Leadership Plus, was developed by Oklahoma People First members who identified the need for basic leadership skill training during a statewide self-advocacy conference. Many members had been placed on boards and committees and were eager to serve. However, they often did not feel involved, supported or important to the group process and were therefore stuck in roles without direction. Leadership Plus was created to help alleviate this predicament by assisting more people with developmental disabilities to acquire the basic leadership skills necessary to serve as consumer representatives on boards and committees.

Leadership Plus focuses on how and why leadership skills are developed, responsibilities as consumer representatives, why boards and committees exist, and the meeting process. Other components of the training relate to communication, and making group and personal decisions. The training takes approximately eight hours to complete, and is conducted in a classroom-type setting using discussion, role playing, group games, and small group activities. Leadership Plus is designed to be led by anyone with leadership experience, including consumers who have previously participated in a trainee capacity. In addition, past participants are often asked to serve as support persons for new participants.

Since the training began in 1992, 60 people have participated in the Leadership Plus program in Oklahoma and the majority are actively serving on boards and committees. Pre- and post-program evaluations indicate that participants have gained increased knowledge about meeting processes, consumer representation, and how to become a board or committee member. In addition to training in Oklahoma, the program is being presented in over 35 states, Mexico, and Australia. In some instances, local self-advocacy groups, residential providers, and others present the Leadership Plus materials, and on other occasions Oklahoma People First staff travel to other states to conduct training.

> Throughout the Leadership Plus training one theme remains constant: If you don't understand something, ask questions until you do understand. And if people don't understand you, keep talking until they do.

A side piece to the training is *I Make A Motion Too....*, a pamphlet designed to assist board and committee members in supporting consumer representation. The publication discusses the need for consumer participation on boards and committees, especially those that serve people with disabilities. It has been requested by groups around the country, and users indicate that it helps them make the case for the participation of people with disabilities.

Throughout Leadership Plus training one theme remains constant: If you don't understand something, ask questions until you do understand. And if people don't understand you, keep talking until they do. Real leaders ask questions. Real leaders make sure people understand them.

Michelle Hoffman is Self-Advocacy Coordinator for the Tulsa ARC, and serves as the advisor to Oklahoma People First, a program sponsored by Tulsa ARC. For further information about Leadership Plus training or materials, contact Michelle at (918) 582-8272. Leadership Plus is funded by the Oklahoma Planning Council for Developmental Disabilities.

Being a Leader: Leon Barrett

My name is Leon Barrett. I live in Tulsa, Oklahoma. I have some things that I would like to tell you about my experiences in being a leader.

I first learned about being a leader in People First. I really wanted to do it, to be a leader. But, I didn't really know how. I started out by being secretary in our local group. Now I'm vice-president. But, it took time to get here. I also serve on the Tulsa ARC board of directors and as a member of a human rights committee. All of this has taught me a lot. I am proud that I am able to help people by being on these things.

I took the first Leadership Plus training and it was fun. In that training, I learned that I can do it, I can be a leader. And I learned that if you don't understand something, then it's your responsibility to ask questions until you do understand. I try to do that. Sometimes it's hard because people have a hard time listening to my questions. Sometimes I am too shy to ask and I think that people will think my question is stupid. That's hard. I'm still learning about that.

A person who is a leader is serious about what they are doing as a leader. I am serious. A leader also respects people, listens to people, and looks people in the eye.

When I lived in institutions, I did not have a chance to be a leader because the staff did everything. I have learned a lot from my friends Joe and James. They have taught me that I can be a leader, be active, and make a difference. Watching others has helped me learn to be a good leader.

If I could give advice about helping people be on committees, I would say:

- Help people understand what the committee is for. It is frustrating when you don't know why you are there.
- Explain things in easy language. I get confused when people talk way above my head, especially with the budget.
- Summarize information. Don't give anyone a bunch of stuff to read because people don't.
- Make sure people are supported. James helps me on the ARC board. It's good to have someone that you know you can turn to.
- Stop the meeting if you don't understand. Sometimes I am too afraid to ask. Leaders should ask questions like, "Does everyone understand?" Sometimes groups have so much to talk about that they don't want to stop. When that happens it tells me that they really don't care if I understand or not.
- If you say you are going to explain something to someone after the meeting, then do it.

That's all I have to say about being a leader.

Leon Barrett is a self-advocate and vice president of People First, Tulsa, Oklahoma.

Building a Network of Leaders

by Jill Flynn

Leadership can be a hard word to truly understand. It means many different things to people. I tend to agree with Napoleon Bonaparte: "A leader is a dealer in hope." Leadership is based on a vision or dream supported by a group of people who work together to reach it. Leaders can see others' abilities and get them actively involved. A leader helps others become better leaders by working with them, listening to them, and acting on their hopes and visions.

The Oregon Developmental Disabilities Council has often worked with self-advocates who desire to be strong leaders, providing opportunities to go to trainings and speak at public hearings, task forces or panel presentations on self-advocacy. This has helped individuals to grow as leaders, but several years ago the council also saw the need to provide more opportunities for these leaders to make their own connections and work together.

> The initiative supports the building of a viable network of individuals with disabilities who are interested in being active as leaders on the state level.

In 1992, staff from the DD Council and one of its projects, Community Partnerships, met with People First of Oregon board members and advisors to discuss self-advocacy in Oregon. People First members described barriers to leadership that existed in the community and the supports they would need to overcome those barriers. Members raised issues such as communication with other self-advocates, transportation, and getting and keeping advisors and support people. The idea of a self-advocacy initiative developed out of these discussions and the DD Council's desire to support broader networking and collaboration by self-advocates exercising leadership.

In 1994, an initiative was written, presented to, and passed by the People First of Oregon board, and supported by the DD Council. The initiative supports the building of a viable network of individuals with disabilities who are interested in being active as leaders on the state level. To help achieve that goal, the council and Community Partnerships offered to work with People First to support three areas of activity: support and strengthen existing People First chapters, develop new chapters, and expand the political influence of self-advocates in Oregon.

The initiative provides a small amount of money to support the work. To make the most of limited dollars, Community Partnerships pays salaries and the DD Council adds in-kind support with materials and staff support. Two part-time staff people each work 30 hours per month on the initiative: Judy Cunio, one of the original founders of People First of Oregon, and Michael Bailey, an active community organizer and the parent of a child with a disability. They strengthen existing chapters by offering advice, ideas, and other assistance related to needs such as finding advisors, arranging transportation, running a group, working together, finding support people, and fundraising. They support new chapters by coordinating assistance and personal visits from existing chapters. And they encourage expanded political influence of self-advocates by working with Community Partnerships staff to adapt existing advocacy training materials and write them in easy-to-understand language. In addition, they support the involvement of interested self-advocates in monitoring their own services, in voter registration drives, and in building advocacy teams in communities to educate policymakers about issues and help them change their attitudes. They also respond to phone calls on a toll-free number, maintain an updated listing of self-advocates in Oregon, and gather information on how other states' self-advocacy groups work.

This past March, a planning meeting was held to identify additional steps to be taken by the initiative. People First members were very clear about what they wanted: training and education for social service agencies, direct-care staff, and employers about self-advocacy; leadership training for the state and local boards; help to format and mail a newsletter; advisor training and support; assistance in strengthening communication between members; and resource materials on running meetings, community organizing, fundraising, and team-building. They also requested aid in identifying training that is available for self-advocates in skills such as listening, assertiveness, mediation, and negotiation. Initiative staff are currently seeking individuals who have skills in these areas to assist with trainings so that self-advocates can become better leaders and involve others in their communities.

> The intended outcome of the initiative is a team of strong leaders within the People First movement...

The intended outcome of the initiative is to develop a team of strong leaders within the People First movement who can work with other teams in Oregon, be active partners in policymaking and legislative efforts, and help convince the people of Oregon of the contributions people with disabilities can make. The DD Council and Community Partnerships will continue to support People First of Oregon in strengthening existing chapters, establishing new chapters, and expanding the political influence of people who have disabilities as we work to realize our common vision of independence and dignity for self-advocates in communities around the state, nation, and world.

Jill Flynn is the Self-Advocacy Coordinator with the Community Partnerships Project, Oregon Developmental Disabilities Council, Salem. For further information on the Oregon self-advocacy initiative contact Judy Cunio or Michael Bailey at (503) 945-9229.

Judy Cunio: What Makes a Good Leader?

Over the past 21 years, I have developed leadership skills through a lot of practice in various roles. It takes time to find out what works and what does not work, how you relate to people and how they relate to you. Being a good leader has a lot to do with your attitude and why you have taken on that role.

A leader has to care about the people they are leading and believe in the things they are doing. There needs to be a commitment. A leader will follow through; if they say they will do something, they will do it. That is one way a leader needs to be an example to other people. The person who is a leader needs to be confident and motivated. One of the big differences between leaders and anyone else is that a leader must be able to delegate, to get people involved. If you do all the work, others don't get involved. Leaders are outspoken and they need to have confidence to know that they are able to lead. This does not mean that they should take over, but they keep people on track.

Now that I have said so much about what a leader is, why do I call myself a leader? I hope that I am a good example, that I live what I say. I want people to see that when I say something, I mean it, that I am not a hypocrite. I hope that I encourage people to do things themselves. I think I am pretty assertive and try to be direct when I communicate. At the same time, I hope that I am sensitive to how other people feel and motivate people to share their ideas. I try to give them a chance to give their opinions and say "yes" or "no."

As many leaders have in the past, I have faced challenges in my role as a leader. The biggest of these is communication because I am hard to understand. Even if it is hard for people to understand me, I still have to be able to get my message out. I have trouble doing that because sometimes people don't take me seriously. At those times I try not to get frustrated because that only makes it worse. I think my speech is hard to understand. I try to get help from people I know will understand to communicate my ideas. I also have a Realvoice computer (that I call Mabel) which helps me to present speeches.

Working with Oregon's self-advocacy initiative gives me an opportunity to do something I know I can do. Community Partnerships staff give me the supports I need to carry out my responsibilities and they treat me like a colleague. That's important; it gives me more confidence in myself. I hope the work I do will help make People First strong and make the organization better, not only for me, but for all of the people who are involved. It will empower people to continue to grow and develop their skills and do what they want.

If that happens, my job will not be necessary. So what do I see myself doing in the future? I want to be a writer who has the ability to impact people. I have proven to be the strongest as a leader when I write. When I write, I have a greater impact on people, I can make them think and better understand. I plan to continue my writing to bring up issues that people need to know about and understand. I like to make people think.

Judy Cunio is one of the founders of People First in Oregon, and is currently a staff member of the Oregon self-advocacy initiative. The above photo was taken during legislative training at the State Capitol, during which Judy (with hand raised) sparked discussion among other self-advocates by sharing her experiences in talking with legislators.

Civic Leadership: *Youth in Government*

by Polly Harrison

Minnesota offers many experiential opportunities for adolescents to develop civic leadership skills, but none are as large or as inclusive as the Minnesota YMCA Youth in Government Model Assembly Program. Under the direction of former State Representative Peter Rodosovich, over 1000 eighth through twelfth graders annually perform roles in the mock executive, legislative, and judicial branches of state government. The program encourages life-long, responsible citizenship by providing experiential learning for young people interested in public issues, and providing forums for recognition of the abilities and capabilities of youth.

> The program encourages life-long, responsible citizenship by providing experiential learning for young people who are interested in public issues...

Over the past four years since youth with developmental disabilities have begun participating in the program, 38 have been involved, with 11 students with developmental disabilities participating in 1995. Most of these students have gotten their start toward the Model Assembly Program through the YMCA's inclusive Leadership for Empowerment (L.E.P.) Program. The L.E.P program is a service-oriented leadership program involving junior high/middle school youth with and without disabilities throughout the state. Participants develop an appreciation for individual strengths and how to work together to serve the broader community. The program also sponsors an inclusive leadership camp each summer and serves as a resource for YMCAs and other youth development organizations working toward full inclusion. The L.E.P. program was the catalyst for establishment of the inclusive Model Assembly program and continues to coordinate support for youth with developmental disabilities during their participation by coordinating transportation and securing interpreters and personal care attendants.

The Model Assembly program begins each September with the formation of delegations at YMCAs and high schools around the state. The participants register for a particular program area – Senate, House of Representatives, Court of Appeals, Supreme Court, Cabinet, news media, and lobbying – and then the work begins at the delegation level. Depending upon their program area and role, delegates engage in a variety of activities. For participants who aspire to run for office, there are speeches to write and campaign strategies to develop. Those filling the roles of senators, representatives, and lobbyists determine positions on issues and express them through authoring bills and position papers. Media correspondents attend training to learn how to write news stories and operate broadcast equipment. Delegations rely on local resources and adult professionals to help them with their work.

In October, the State Convention is held (a replication of a party convention) in which delegates elect their governor, lieutenant governor, chief justice of the Supreme Court, chief judge of the Appeals Court, secretary of state, attorney general, president of the Senate, and speaker of the House for the upcoming Model Assembly session. The annual culmination of the program is the four-day Model Assembly session held at the State Capitol in January. During the session, delegates have the opportunity to act as senators and representatives, governor and lieutenant governor, attorneys and judges, legislative pages, lobbyists, and press corps. It begins with the swearing in of officers, which is close-circuit broadcast to all program areas. The program areas then get to the business at-hand, which includes committee meetings for the House and Senate, arguing cases in the Court of Appeals and Supreme Court, and meetings for the media correspondents to determine coverage and assignments. While some pages are busy running messages for the legislators, others learn about the three branches of state government through an educational series running throughout the session.

> The presence of youth with disabilities has benefited not only those youth, but has also contributed to this learning experience for others by demonstrating that leaders evolve from every part of our diverse society.

The only adaptation made so far to the structure of the Model Assembly program for participants with disabilities is to have each participant with a disability register with a nondisabled peer as a team. The two are usually friends or peers from the same school. They work together throughout the program, whether it be authoring an article for the newspaper or following bills as members of the Governor's Cabinet. While there is currently no formal training specifically related to supporting a partner who has a disability, teams have functioned well because most members have known each other from the L.E.P. program and worked together previously. If problems or questions arise, staff are available to provide information and assistance.

During the 1995 Model Assembly, there were two teams in the Cabinet and Humphrey House, four teams that worked as pages, one team in the Court of Appeals, and two teams in the press corps. One of our proudest moments came when three of our page teams at the page mock convention had a candidate on the final ballot for speaker of the House, president of the Senate, and the governor ticket. Additional highlights included the Court of Appeals team earning a decision in their favor – the only appellate team to do so on that particular case – and three of the Cabinet members being interviewed for the final edition of The Capitolist, the Model Assembly's daily newspaper.

Opportunities such as the Model Assembly program have a far reaching impact on all the youth who participate. They develop stronger leadership skills, expressing their views with confidence and conviction, learning to work as team members, and listening to and respecting one another. They take these skills back to their schools and exercise them in their L.E.P. groups and other activities. The presence of youth with disabilities has benefited not only those youth, but has also contributed to this learning experience for others by demonstrating that leaders evolve from every part of our diverse society.

Polly Harrison is a Youth Development Specialist with the YMCA of Metropolitan Minneapolis, Ridgedale Branch. She is the director of the statewide Leadership for Empowerment Program and coordinated the inclusive efforts of the 1995 Model Assembly. For additional information on the Youth in Government Model Assembly Program, contact Polly at (612) 544-7708.

Experiencing Leadership in Government: Mark Terauds

My name is Mark. This was my second year in the Youth in Government program. Both years I have been a member of the Governor's Cabinet. A cabinet member follows bills through the legislative process. I had to fill out forms and report to the rest of the cabinet on how the bills were doing. Being in Youth in Government helps me understand my government classes at school better, and it's a more fun way to learn.

The first year I was a little nervous because I was worried about making a mistake. But, this year I knew what to expect. My confidence was stronger and I could start doing my job before someone asked me to. Some people who were on the cabinet this year did it last year, too, and I remembered them.

Besides being in the cabinet, there was lots to do that weekend. We all stayed in a hotel and at night they had activities for us. I liked singing karaoke and sang *Puff the Magic Dragon* twice, once as a solo and once with a group. The D.J. gave me some cool sunglasses for doing a good job. The cabinet went on a tour of the house of James J. Hill (founder of the Great Northern Railroad) and we met with the governor's press secretary.

As a leader in the Youth in Government program, I had to work hard and let people know how the youth governor felt about bills. I think leaders have to work hard and have to like to help people. Sometimes people don't want your help, though, and you have to listen to them. A leader also has to be willing to take risks sometimes, like when you have to stand up and talk or sing in front of people. I liked being in Youth in Government because it made me work hard. I met lots of people and had fun, too.

I'm a leader at school, too. I'm an actor in the group Y's Act, and we just put on a play about violence in the media. Soon, I'll be working, but even through I'm busy I want to go to Youth in Government again next year.

Mark Terauds is a high school junior and lives in the Minneapolis suburb of Eden Prairie.

A School for Community Leaders

by Carolyn Lejuste

At the Leadership Development School for People with Disabilities (LDS) we believe that – given an opportunity, some resources, and a little support – people with disabilities can identify and solve their own problems. Through the process of identifying a community issue they wish to address and working with others to influence the issue, participants in the program acquire leadership skills and develop their own unique leadership styles. As they attend six weekend training events held over a nine-month period, participants grow in their ability to be in charge of their own lives and the disability rights movement, and return to their communities as self-confident and determined leaders.

The LDS program is driven by the self-identified needs of participants. Individuals attend in teams of four, and with the assistance of a LDS staff coach each team identifies an issue around which they develop a project in their home community. Team projects are structured around a Participatory Research model as defined by Peter Park in the book *Voices of Change*. Participatory Research teaches people to identify questions related to an issue, seek information through research methods that stand up to academic rigor, and create a strategy for use of the information to advocate for change. It is an opportunity for people who have been the objects of research to assume an active role in uncovering knowledge that is important to their lives. In the process, teams connect with others who are interested or involved in the issue and enlist assistance in solving the problem, which builds group capacity. Team members develop skills in communication, assume responsibility for follow-through, and learn to trust one another.

Program activities and participant behavior are guided by three values identified by the first year's class: respect, inclusion, and responsibility. One challenge to upholding these values while meeting individual participant needs and pursuing a goal is that the needs of participants are sometimes contradictory because they have various kinds of disabling characteristics – cognitive, emotional, and physical. As they work together, participants develop ways to accommodate one another and also examine biases or assumptions about people with different disabilities. For instance, individuals with speech characteristics need additional time to be understood. Consciousness-raising occurs as their peers take the time to listen to them and examine commonly-held assumptions of cognitive disability in persons with speech difficulties. Concurrently, participants become aware of assumptions regarding people with cognitive disabilities. Accomplishing tasks while involving and respecting everyone encourages the development of relationships in which all are noticed and appreciated for what they offer.

Another challenge in LDS is that people with disabilities have often been socialized to be dependent on other people or on the system that supports them. The environment within LDS demands that participants take responsibility and action in their lives. Moving away from dependency has implications for change in the behavior of professionals, family members, and people with disabilities alike. For professionals and families, the challenge is to understand and accept that things will be different when people with disabilities are in charge of their own lives, choices, decisions, and rights movement. And for people with disabilities, the challenge is to recognize and change habits of dependence.

Because participants have often been discouraged from practicing their leadership skills within their home communities, LDS has designed the program to increase the opportunity for direct support. By accepting teams, the program encourages the development of peer supports that hopefully will continue after attending LDS. In addition, a coach is assigned to each team to listen to and support individuals, ask questions to help clarify project goals and tasks, and organize the design of the training based on the needs identified by the participants. The coaches, some of whom were participants in the first year's class, are people with disabilities who are working hard to understand ways of developing new leaders and put that knowledge into practice.

The impact of the LDS approach can be seen in the projects that teams are carrying out, and the manner in which team members are working together. For example, a team from Kalamazoo is researching models of screening and training personal assistants. In the process, they have noticed problems in communicating with one another. They are now also researching and practicing different ways of listening to each other and giving feedback. A team from a local People First group is researching transportation issues. They are concerned about bus delays and are tracking the number of times that their own buses are late. They are also looking at who is really in charge of transportation money and decisions, and have written letters to the governor to express their concerns. And a group from the Upper Penninsula is working to establish an advocacy organization, and is in the process of organizing an event that will bring together other people with disabilities who may be interested. These and the other team projects demonstrate the truth of the belief underlying the LDS approach: given an opportunity, resources, and support, people with disabilities can solve their own problems.

Carolyn Lejuste is the Administrator of the Leadership Development School for People with Disabilities. She may be reached at (517) 487-1755. The school is a three-year project of Michigan Protection and Advocacy Service in Lansing, funded by the W.K. Kellogg Foundation.

Crossing Barriers: Kelly Watson

A leader is responsible. A leader is someone who sees a need in the community and has the commitment to take it on. But, he/she recognizes that the issue cannot be handled by one person. A leader has to have the ability to get other people involved in the issue and be willing to delegate responsibility to get things accomplished.

Recognizing leaders is sometimes confusing. There are people who do not see themselves as leaders. They take on a problem/issue and just do it. Other people who call themselves leaders want personal recognition and try to take all the credit for getting something done.

One of the ways that I'm a leader is that I care about and understand what's happening in the disability community; I see the injustices, oppression, mistreatment and abuse that I and other people with disabilities receive from society. Another way I see myself as a leader is that I always try to think of the group's needs first. I try my best to accommodate other people's needs, yet keep them focused and moving forward. If I know there is a communication problem within the group, I make the individuals deal with it. I try my best to listen before making a judgment or telling people what to do.

One barrier to becoming a leader, as always, is the attitudes that society has about people with disabilities. The nondisabled community has a lot of preconceived notions about the disability community. That makes it hard to deal with an issue. A good example is my speech characteristic (or my CP accent as I prefer to call it). When I get involved in a project and the people don't know me, they often patronize me because I can't speak as clearly as they would like. They assume that because of my speech I don't know what I'm talking about.

Another type of barrier is paternalism. Because the nondisabled community is so used to taking care of people with disabilities, it's hard for them to give us the opportunity to make our own decisions. There are two issues here. One is they are afraid we can't think for ourselves, and therefore we will make the wrong decisions. The other is that it has been their job for so long to decide what's best for us that they have trouble relating to us as equals.

Political savvy is another challenge that I face as a leader. What I mean by this is that you have to know when to be strong and take a risk by stepping forward, making your views known. A lot of times these views are new to the group and they may be opposing views. People like this about me; it is one of my strengths. It also encourages people to try to get me to take on the role of spokesperson for different organizations. Before taking the role on, I have to think about things I'm already involved in. I have to question whether it will hinder any of the other projects I'm involved in, and ask if it's going to build my own network/coalition. As a leader I have had to learn to say "no" in order to remain effective in my chosen projects.

One way in which LDS assisted me is that it provided me with networking experiences. I met people from around Michigan. This helped me a great deal because it allowed me to share my ideas with them and get people's feedback on my projects. Also, by attending LDS weekends I learned about different techniques of communication within groups. I learned that my techniques of communication and my ideas about how to achieve goals were not so atypical. This was very affirming to me as a leader. Another support I received from LDS was that people were there to listen to my concerns, problems, and issues regarding leadership. This is very important because some people outside of the advocacy realm cannot relate to what advocates experience.

One of my future interests is to get insurance funding for service animals. Service animals offer a great deal of independence to people. They are a form of assistive technology service that is not paid for yet by public or private insurance. Those of us who rely on service animals have to rely on the good hearts of other people to buy our service animals.

I would like to continue to talk about LDS on the national level. My goal is to help spread the word about the LDS model to other states. I would like to be involved either in bringing students from other states to our school in Michigan, or in designing regional LDS programs in other parts of the U.S.

Kelly is one of the Leadership Development School (LDS) team coaches and also was a member of the first year's class. She has cerebral palsy and is dependent on technology, including her service dog, to live independently. Her project at LDS was to get service dogs and personal assistant services included in the definition of Michigan's Assistive Technology project (AT). Her efforts led AT and Michigan Protection and Advocacy Service to include service dogs in their case priorities.

Culturally Diverse Leadership: A Model of Inclusion

by Betty Horton

Sweeping reforms are occurring in the disability field. The consensus, by professionals and persons with disabilities alike, is that the old system does not work. Radical changes are occurring at all levels – from public policy, to services, to person-to-person interactions. The reforms seek to accomplish two goals: full integration of people with developmental disabilities into public life, including schools, the workplace, and the community; and the extension of all the rights and responsibilities of citizenship to a group of people to whom they have historically been denied. By far, the more fundamental reforms have to do with changing the status of persons with disabilities from outcasts to full citizens. This status change is reflected in terms such as "self-determination," "empowerment," and "leadership."

Reform initiatives aimed at full inclusion and citizenship move us closer to fulfilling the promise of civil rights for people with developmental disabilities that began on the heels of Brown v. Topeka Board of Education in 1954. Ironically, the one group that remains, "the most locked out and left behind" are culturally diverse people with disabilities (Williams, 1994 p. 52). The reasons for the exclusion of African American, Hispanic/Latino, Native American, and Asian American people with developmental disabilities from leadership roles in and as a result of reform initiatives are many. More important than the reasons, however, are the actions taken to correct the situation.

■ A Vision for Inclusive Practices

The beginning point of every reform initiative is to create a vision of what is desired. One example of vision statements for inclusionary practices in relation to culturally diverse persons with disabilities can be found in the following statements that guide the activities and gauge the progress of the Inclusive Practices for Culturally Diverse Persons program at the University of Kansas:

- **Vision 1**. Culturally diverse persons with disabilities, their families, and culturally diverse professionals are fully represented as key planners, organizers, speakers, and participants at every conference and meeting.
- **Vision 2**. Culturally diverse persons with disabilities and their families, and culturally diverse professionals are fully represented on advisory boards, planning committees, and in executive positions of key agencies and organizations.
- **Vision 3**. Culturally diverse persons with disabilities and their families, and culturally diverse professionals are fully represented in key leadership roles in universities, service agencies, and in organizations.
- **Vision 4**. Culturally diverse persons with disabilities and their families, and culturally diverse professionals are satisfied with the range of options and opportunities for participation and leadership in university, service agencies, and organizational settings.

These vision statements reflect the program's belief that the leadership of culturally diverse persons with disabilities represents a vast, untapped resource. Persons with disabilities must be given opportunities to become strong enough to participate within, share control of, and have an influence on events and institutions affecting their lives. We believe that our job is to help young persons with disabilities help themselves and others. For these reasons, the goal of the program is to provide opportunities for culturally diverse persons with disabilities to "show and grow" their leadership skills.

■ A Process for Inclusive Practices

After the vision statements were developed, the next question was: Where should we begin? In Kansas, we began with a statewide conference called Building Community Supports for Culturally Diverse Young Adults with Disabilities and Families: Strategies for Inclusion. Twenty-eight young adults and their family members from Caucasian, African American, Hispanic/Latino, Native American, and Asian American backgrounds participated in planning the conference, and presented sessions on such topics as housing and independence, communicating with service professionals, and employment barriers. Additionally, the families and young adults each invited an influential person (e.g., school superintendent, agency director, mayor) to become their exclusive partner for a day at the conference. The purpose of the conference was to help set the stage for young persons with disabilities, families, and influential leaders to become partners in reforming services and delivery systems. During the conference, the young adults and their families were recognized as the experts, and their views of services and service delivery issues were sought by the policymakers and professionals. In particular, the role of the young adults was to lead the discussion by sharing their perspectives, providing information, and advocating for themselves and others.

Feedback from participants has indicated that the conference was a success in several ways. First, many participants reported that it debunked myths and misconceptions they had held about each other; instead of concentrating on disability or racial labels, participants got to know each other personally. Secondly, the professionals and policymakers became newly aware of a cadre of potential leaders who are culturally diverse and have disabilities. Thirdly, a sense of community and mutual respect was generated among participants; many, particularly those who were partnered with each other, have continued to keep in touch. And lastly, young adults and their families had an opportunity to become "insiders" as a result of the exposure and visibility given them in their leadership role; for instance, several of the young people have been invited to become board members of non-profit or state agency councils.

■ Conclusion

This conference began with the premise that professionals and others can take certain steps to set the stage for leadership by culturally diverse persons with disabilities and their families. As we continue to follow the vision of full inclusion of all citizens with developmental disabilities, the challenge will be to resist the tendency to be satisfied with just a little progress. Every university, agency, and organization must pull together until people with disabilities from African American, Hispanic/Latino, Native American, and Asian backgrounds are fully represented as participants and leaders in every aspect of the current reforms.

Betty T. Horton is an Assistant Research Professor at the Kansas University Affiliated Program (UAP)/Lawrence and is the Chair of the Work Group on Cultural Diversity. The Inclusive Practices for Culturally Diverse Persons program is a collaborative effort of the Kansas UAP, Kansas Council on Developmental Disabilities, Kansas Protection and Advocacy Services, Cerebral Palsy Research Foundation of Kansas, Kansas Department of Social and Rehabilitation Services, and other agencies and organizations. For further information contact Betty at (913) 864-4950.

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Leadership and Ambition: Askia F. Adams

Hello, I'm Ski, and I want to share with you what I would like and how my team of people (my brother, mom and dad, school advisors and others) have been trying to help me get those things I want. I don't consider myself a leader. I enjoy the challenge of working toward a goal. I like trying to prove others wrong. Like in debate; I used augmentative communication using the laptop computer and synthesized speech. The teacher said that I helped him learn to accept people that are somewhat different.

I am physically challenged and have a speech impediment. I can do things other students can do, but it takes me longer. I want to become a special education teacher in elementary school. Several years back I wanted to be a computer programmer, and would still like to get a degree as a backup in computer programming.

To get to my goals, I decided in middle school I wanted to go to college. I realize it might take me awhile to get through college. I also told my parents then that I did not want to live at home after graduating from high school. My plans are to go to college, get a job, and have my own apartment or home.

My parents, school teachers, vocational rehabilitation counselors, and an agency called WDDS are helping me work toward my goals. The school has provided me with speech, occupational and physical therapy, assistive technology, and vocational counseling. My vocational counselor at school has helped me to evaluate my strengths and weaknesses as well as look realistically at my future needs. My 10th grade year I had a pullout class called Career Decision Making, a mini-course where your values and interest are assessed. Ms. McBeath also helped me look into taking a class at a vocational school in microcomputers, but I decided I'd rather take classes that would help me get ready for college. WDDS has helped me after school by providing a personal attendant who helps me until my parents get home or goes with me on outings for social things. I'm on their waiting list for independent living referrals when they become available and I'm ready to move away from home.

I don't really know what will happen after college, but I hope there will be an agency out there that will help me get a job, a job coach, housing, and other support to live my life as an average person.

Askia F. Adams is a 17-year-old senior at F.L. Schlage High School in Kansas City, Kansas. He has maintained a 4.0 average grade point in high school, is ranked first in the entering senior class at Schlage, and hopes to be considered for valedictorian. One of his hopes is to be able to stand and walk at the graduation ceremony.

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Learning to Lead... Leading to Learn

by Michael N. Sharpe

Within the past decade, one of the fastest growing curriculum options that has become available to secondary school students in the United States is the opportunity to enroll in courses that help to define one's role as a socially responsible member of society. Typically, such courses are designed so that students are given the chance to participate in cooperative learning and team building activities, but it is intended that these skills will ultimately have broader application in addressing social issues.

Once predominately the role of social and religious organizations, educational institutions have recognized the need to move beyond traditional curricular paradigms to promote learning opportunities aimed at enhancing personal growth and development within the context of social consciousness. Whether the focus of instruction involves service learning, peer mediation, or activities involving collaborative teams, a factor essential to each is the concept of leadership.

As a discipline, the study of leadership has undergone a rather dramatic change, from an early trait model that suggested that leadership skills were reserved for a few, to a more contemporary view that focuses on personal empowerment and development of skills that are within the grasp of virtually everyone. The curriculum developed for the Learning to Lead...Leading to Learn project exemplifies this latter perspective, adopting the view that all persons have the ability to lead in their own way. That is, although each person will use a certain leadership "style" and be faced with their own unique set of leadership challenges, it is a basic premise of the project that everyone has the capacity to learn and apply leadership skills.

The Learning to Lead...Leading to Learn project commenced in 1992 as a collaborative effort on behalf of the University of Minnesota's Institute on Community Integration, Minnesota 4-H Youth Extension Services, St. Paul Public Schools, and the Rum River Special Education Cooperative. Implemented in a multiple phase sequence, one of the key objectives of this demonstration project is to develop and promote the leadership skills of groups of youth with disabilities. By doing so, it is anticipated that the project will address the pervasive problem of the lack of control youth with disabilities exercise over important aspects of their lives by helping them to develop the skills necessary to assume leadership roles in society.

The project was launched by conducting a comprehensive literature review of leadership programs and activities designed for youth, particularly projects that have employed innovative methods to include groups who have been excluded or underrepresented in society. This effort was augmented by conducting extensive data collection activities, both through focus groups and applied survey research. Focus groups were conducted to identify key issues specifically related to the topic of leadership and persons with disabilities. Participants included multiple groups of students with and without disabilities, parents of students with disabilities, general and special educators, community leaders, and adults with disabilities. In addition, two sets of leadership scales were developed and administered to groups of teachers, parents, and students with and without disabilities. Their purpose was twofold: to ascertain the extent and general nature of leadership skills possessed by youth with disabilities, and to determine the degree to which they were given the opportunity to exercise leadership skills in the course of their daily lives.

In addition to these research initiatives, project staff, supported by public school and 4-H staff, engaged in the design and development of a leadership curricula currently being implemented in a total of four demonstration sites in the St. Paul Public Schools and the Rum River Special Education Cooperative. Each demonstration site includes groups of youth with physical disabilities or mild mental retardation along with cohorts without disabilities. Within these groups, youth participated in a series of activities that emphasize important components of leadership. Developed as 18 skill-building activity units, the Learning to Lead... Leading to Learn curriculum covers the following topics:

- What is Leadership?
- Self-Awareness and Self-Esteem
- Individual Differences
- Identifying Ways to Lead
- Communication
- Assertiveness
- Teamwork
- Group Facilitation
- Parliamentary Procedure
- Problem-Solving
- Conflict Resolution
- Advocacy and Self-Advocacy
- Leadership Issues and the Future

A key feature of this curriculum is the development and initiation of an individual leadership plan. In generating this plan, students identify the ways and means through which they will work to achieve objectives in leadership areas for which they have expressed a personal interest or challenge. In support of this effort, students also engage in mentoring activities with their choice of peers, educators or leaders within the community. Finally, as a means of monitoring individual student progress, a series of objective-based assessments are used for each unit of the curriculum.

Upon completion of the implementation phase, an extensive review will be conducted with group facilitators to assess what aspects of the curriculum need to be changed or modified to ensure a quality product. This will be accomplished through individual and group interviews with participants and by reviewing notes and other documentation maintained by facilitators. Once the information has been compiled, the curriculum will undergo final revision and be available for distribution to special educators across the country in late 1995.

Michael N. Sharpe is Coordinator with the Learning to Lead...Leading to Learn project at the Institute on Community Integration, University of Minnesota, Minneapolis. For more information about the project and curriculum, contact him at (612) 624-0096. The project is supported by a grant from the U.S. Department of Education, Office of Special Education Programs.

Choosing to Lead: Theresa Maefield

Theresa is an excellent example of the highly motivated youth participating in the Learning to Lead...Leading to Learn project. A 19-year-old student who is in the 12th grade, Theresa is a vivacious young woman who likes to interact with others. When asked to describe herself, she says that she is a "nice" person who has a sense of humor that makes people laugh, and that she has set many goals for herself. Along with math and English classes, she is involved in a special education program through which she has the opportunity to engage in job training and work activities within the community. Participation in this program supports Theresa in working up to 35 hours a week at a supermarket to earn money and help maintain a household with her mother, grandmother, two brothers, and a sister.

Despite her highly industrious nature and commitment to her job, Theresa made a decision to forego an afternoon of paid work once a week in order to participate in the Learning to Lead...Leading to Learn project. She says that she likes participating in the project because she gets an opportunity to interact with other students, share her opinions on the subject of leadership, and learn from others as well. To Theresa, being a leader means helping others, knowing what you want in life, setting goals for the future, and speaking up for yourself whenever necessary. While she feels she is a leader at times, she says that there are times when she does not lead because "even persons with stronger leadership skills can't be expected to be leaders all of the time."

Theresa sees herself as "a little bit of a leader" and is interested in learning and using new leadership skills in the future. Aside from acquiring leadership skills, participating in the project has helped her to learn more about herself as a person and as a potential leader. While she feels it is more challenging to take on the role of a leader in new situations or with new groups, she always tries to give it her best effort. Along with the weekly sessions that cover some aspect of leadership development, Theresa says that she enjoys the opportunity to work with a mentor and see how leadership skills can be applied in the community. Because she feels she has grown as a result of her experiences in the project, Theresa has expressed an interest in continuing to be involved in leadership activities in the future.

When asked about her plans for the future, Theresa says that she wants to continue her education beyond high school and pursue a career in the area of child care. She has worked with young children in such settings as youth camps and babysitting, and believes she can use these skills in a career. She is currently exploring academic programs that are available at local technical colleges.

Theresa Maefield is a senior at Highland Senior High School in St. Paul, Minnesota. She was interviewed for this article by Louise Tetu of the Learning to Lead...Leading to Learn project.

Students in Community Leadership

by Julie Schreifels

In Minnesota, Community Transition Interagency Committees (CTICs) have been established by state mandate to improve local services and supports for students with disabilities who are in transition from high school to adult community living. Across the state, over 70 CTICs comprised of school staff, business people, community services personnel, parents, and students with disabilities provide leadership in meeting the transition-related needs of youth and young adults ages 14-21.

The Goodhue County Education District - Community Transition Interagency Committee (GCED-CTIC) focuses on students in four southeast Minnesota school districts. Among its activities are a futures planning workshop and course to assist students in planning and implementing future adult goals in the five areas of transition: home living, recreation and leisure, community participation, jobs and job training, and post-secondary education and training. In the process of implementing this training, four subcommittees were formed: futures planning, transition fair, parent involvement, and student involvement. The student involvement committee noted that input from local high school students with disabilities would be vital to successfully fulfilling the CTIC's mission to help students with various disabilities become informed and productive adult citizens. Not only can students tell us what they need, but also how to present information in a way that would be interesting to them and their peers.

Various ideas for getting students to participate on the CTIC were initially discussed. These included starting a student group similar to the CTIC, having parent members encourage their children to join the CTIC, and having teachers mentor student members. The idea that sounded most workable was to have each teacher bring an interested student or two to the meetings. The teachers would become mentors for the students, helping them become familiar with the committee process.

As one of the teacher members, I asked my futures planning class for volunteers. Three students volunteered to attend a CTIC meeting and check-out this group of adults. We discussed what the committee does and the basics of being part of such a group. After looking over the agenda together the students – Matt, Jenny, Tricia – and I were off to the first CTIC meeting of the year.

When introduced, the students were met with many warm greetings. During the meeting everyone was initiated with a presentation entitled "What is a CTIC?" The committee then decided on three subcommittees for the year: transition fair, futures planning, and parent involvement. Jenny volunteered for the futures planning committee. Matt and Tricia joined the transition fair committee.

After everyone got into their respective committees, I remember hearing various CTIC members asking the students for their input. For example, the transition fair committee asked, "How long should the break-out sessions at the transition fair be?" Matt and Tricia felt that a half-hour would be long enough, and the committee took their advice. In addition, Matt and Tricia took charge of designing the flyer and banners for the fair and of the CTIC booth, with assistance from other members.

Jenny had participated in the first futures planning

CTIC, continued on page 27

A Student's View of Leadership: Matt Schmolke

I think a leader is someone who stands out in the community. A leader helps people or volunteers in their community. Leaders are different from people who are not leaders because they are more well-known in the community. Leaders are usually in charge of the groups they are involved with.

My leadership roles include student council, Students Against Drunk Driving (SADD), and I am a student representative on the Goodhue County Education District Community Transition Interagency Committee (GCED-CTIC). I am also in a program called Athletes for Outreach for Special Olympics. I volunteer a lot on student council and I helped a lot with the GCED-CTICs transition fair. I made most of the banners and signs on my time. I enjoy speaking up at meetings and try to take charge some of the time. I was a member of the team that put on teamwork inservices in this region. I hope to do more inservices in the future; this experience has helped me be able to stand up and talk in front of more people.

Putting on these workshops has helped me learn how to start off a meeting for the student council or get anything else going. I am more sure of myself when I start a Special Olympics event like our track and field practices. It has helped me out with pretty much anything I do.

I think I would like to pretty much take on whatever I can in the future or whatever I can handle or take on in life. But the thing I would really like to some day take on is my own business or something like that.

Matt Schmolke is a Junior at Red Wing Central High School in Red Wing, Minnesota.

Leading by Serving: *Maryland Student Service Alliance*

by Cathy L. Brill

The Maryland Student Service Alliance engages students with disabilities in service learning – as providers, rather than receivers, of service. Throughout their lives, children who are "different", who have "special needs," are usually recipients of service from others. Getting youth with disabilities involved in service learning turns the tables. Service learning involves them in their communities. They learn about issues and needs, take action to meet those needs, and reflect on their experience. It's a powerful teaching and learning tool that has great potential to prepare community leaders.

Despite the inclusion efforts in schools across the country, isolation from nondisabled peers and the community at large is an ongoing problem for young people with disabilities. By planning service learning projects that include nondisabled peers, students with disabilities are more fully integrated into their schools and communities. As others in the school observe the contributions made by the students with disabilities, they grow to respect the unique capabilities of the group. Rather than seeing the students as a drain on resources, others come to see them as assets to the school. As people with disabilities speak out to demand their rights, they can strengthen their case by making a contribution to their communities and taking on the responsibilities of citizenship through service.

The Maryland Student Service Alliance's special education initiative began with the hiring of a specialist in 1991 who provided ongoing technical assistance to teachers and schools. The specialist worked with a group of special education teachers to develop a curriculum guide and teacher training agendas, and provided on-site assistance in making contacts, finding service sites, planning programs, and dealing with the media. Pilot programs were started in half of Maryland's school districts. In July, 1992, the Maryland State Board of Education passed a service learning graduation requirement for all students, including those receiving special education services. The Alliance worked with school districts across the state to ensure that provisions were made for students with disabilities to meet the new requirement.

Teachers in Maryland have used several approaches to make service learning the engine that drives inclusion at their schools. Some engage students with and without disabilities in projects together, involving general and special educators from the start. Another approach is reverse inclusion; special education teachers start a project with their students, and then include students without disabilities as fellow participants. In this way, the students with disabilities become the leaders. Still other teachers create a program that is so attractive that regular education staff and students want to be involved with them and their students. Teachers also use partial participation in service projects to help drive inclusion; they pair their students with a class of students without disabilities who have complementary skills.

So what do students actually do through the Alliance? The following are some of the service learning projects that are taking place:

- Students with mental mild retardation at a high school serve once a week at a local hospital in various departments – front desk, ob/gyn, cardiology, housekeeping, and patient escort. Students go to the hospital as a group with their teacher, then go to their assigned departments. They keep journals of their impressions and experiences and read books about illness and health care.
- Middle school students with moderate to severe disabilities work on environmental projects with their nondisabled peers. They plant marsh grass to prevent beach erosion, paint storm drains with "Don't Dump" messages, and plant trees. Students learn to work together while they learn science lessons and help protect natural resources. Reflection includes discussion and journals.
- High school students with severe to profound mental retardation work with regular education students to create a disability awareness slide show to be presented to all classes in their school.
- Students with moderate to profound mental retardation at a special school help manage a clothing program for needy families. A group of students travels to the clothing site two times a month to sort and hang clothing and bring back items needing cleaning or repair. Other students at the school clean and mend the clothes in the school. The students have discussed the needs of low-income families. For some of the more profoundly involved students, skills learned are basic and functional, such as sorting pants and shirts, and deciding what needs cleaning.

In a survey of middle and high school special educators conducted in 1992, teachers cited improved self-esteem, more consistent completion of assignments, greater sensitivity to others, improved social skills, and improved relationships with nondisabled peers as outcomes of service involvement for students with disabilities. Through service learning, students gain self-esteem and functional skills in the areas of teamwork and decision-making. They take on leadership roles as they carry out projects, and their status rises within the school and community.

Cathy L. Brill is a staff member with Maryland Student Service Alliance. For more information on the Alliance, contact Maggie O'Neill at (410) 767-0358.

Empowerment Through Leadership Education

by Stephanie Agresta, Betty Aune, and Gene Chelberg

Despite legislation providing full access to higher education for individuals with disabilities, few efforts have been made to prepare youth and young adults with disabilities to function effectively in leadership roles. The University of Minnesota's Project LEEDS (Leadership Education to Empower Disabled Students) is currently in its second year of working to change this state of affairs by developing leadership potential and opportunities for students with disabilities in American colleges and universities.

Traditionally, disability has been viewed as a deficit that resides within the individual. The solution to disability-related problems, in that model, is to "fix" the individual. As a result, students with disabilities have generally been thought of as *recipients* of services, not as *providers* of services or as *leaders*. A new paradigm of disability views disability as a difference. Disability-related problems in this paradigm do not reside within the individual, but rather occur when the person interacts with society. In this view, society needs fixing, not the individual (Gill 1987, 1992; Hahn 1985). The environment must be adapted to accommodate a wide range of differences in our society. Viewing disability from this perspective, it is natural to think of persons with disabilities as potential leaders, ideally suited to guide the way in making our environment accessible to all.

> ...it is natural to think of persons with disabilities as potential leaders, ideally suited to guide the way in making our environment accessible to all individuals.

Project LEEDS is uniquely positioned to fill a gap in leadership education, a field that has not developed approaches uniquely designed for students with disabilities. The project's theoretical model of leadership is a synthesis of competing theories of leadership, with the important additional perspective of disability culture. Students are empowered to envision themselves as leaders and as members of alliances between students and staff with and without disabilities. Further, students gain multiple perspectives on organizations and working within complex systems.

Last August at the University of Minnesota, Project LEEDS hosted the first National Institute on Disability and Leadership. Sixteen student/staff teams from colleges and universities around the nation gathered to explore issues of leadership and identity formation, the nature of power and disability, tools for community building, organizational theory, and the synergy of alliance. One tangible result of the Institute was each team's development of a campus action plan to improve the campus climate for students with disabilities at their home schools. While working to improve the campus climate, Project LEEDS participants have had the opportunity to put leadership skills and theory into practice. The knowledge gained and skills developed through this work will not only make lasting changes in the environments in which the participants live and study, but more importantly, will create a cadre of leaders with disabilities to meet the challenges and opportunities of full societal integration of people with disabilities.

Currently, 1994 institute participants are implementing their campus action plans at their colleges/universities. Incorporating ideas on leadership and disability identity, students and student affairs professionals have undertaken a variety of activities on campuses across the nation. At the University of Texas-Austin, for example, the LEEDS team has developed and implemented a test-taking accommodation policy, as well as sponsored a campus-wide discussion series focusing on combating attitudinal barriers faced by students with disabilities. In Cincinnati, Ohio, at Xavier University, the student/staff team worked with campus stakeholders to negotiate a $20,000 renovation project to establish a centrally located campus office strictly for the Learning Assistance Program. Additionally, team members have worked with students with disabilities on campus to initiate a peer tutor training program. At Sonoma State University in California, team members have created the Disabled Student Organization for their university, as well as consulted with faculty and students in establishing a Disability Studies minor in the curriculum.

> Students are empowered to envision themselves as leaders and as members of alliances between students and staff with and without disabilities.

The LEEDS model promotes the collaboration of students and staff as change agents at their home institutions, and uses this alliance to maximize the personal and professional resources of participants. Professional staff have a unique role to play in effecting institutional change. As leaders themselves, student affairs professionals provide expertise on campus environments and power structures, while also serving as role models and partners to achieve the goals established by each team. Students gain the opportunity to build their leadership skills while also working with campus allies to improve campus life for students with disabilities.

The work of Project LEEDS staff and participants continues. The second National Institute on Disability and Leadership was held in Minneapolis, June 21-27, 1995. Fourteen student/staff teams representing colleges and universities across the U.S. and Canada participated; they have now returned to their home campuses energized and prepared to implement campus action plans. With technical assistance from project staff, last year's participants have begun planning three regional conferences on disability and leadership hosted by Darton College (Albany, Georgia), Moorhead State University (Moorhead, Minnesota), and San Francisco State University to be held in late summer and early fall of 1995. LEEDS staff will also conduct a pre-conference workshop at the AHEAD National Conference, San Jose, California in July, 1995; this workshop will be highly interactive and feature components of the Institute on Disability and Leadership Curriculum. Finally, beginning in the fall of 1995, Project LEEDS will make available at cost its *Disability and Leadership Curriculum Manual* for use in training and development.

Stephanie Agresta is a Graduate Assistant, Betty Aune is Project Director, and Gene Chelberg is Project Coordinator with Project LEEDS, University of Minnesota, Minneapolis. For more information on Project LEEDS, contact Betty at (612) 624-6884. The project is funded by the Dwight D. Eisenhower Leadership Development Program.

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The Project LEEDS Experience: Ivana Kirola

A leader is someone who believes in their cause and wants to encourage other people to stand up for their beliefs, in turn becoming leaders themselves. As a participant in Project LEEDS, I developed my understanding of leadership and disability in ways that have helped me to help others become leaders, as well as assisted me in working with others to improve the campus environment for disabled students.

At San Francisco State University (SFSU) where I am currently enrolled as a sophomore, I've had experiences where I've talked to people who want to bring about changes in the university system. They keep mentioning issues while they talk to me, but are not focused. I've found that Project LEEDS helped me to develop the ability to stay focused on one issue rather than the myriad of issues that so often exist for people with disabilities. Project LEEDS, by hosting the 1994 National Institute on Disability and Leadership, also brought me into contact with other leaders at the national level. Most importantly, the project assisted me with answering the number one question on my mind and I think the minds of others: How does one link the goals of the disabled community and the community at large? I learned that there is not one empirical way to go about answering this question, but that there are many ways. The key to leadership in many cases is allowing development.

Leadership, as with anything else, has its own set of challenges. Acting as a mediator to bring people together on issues is often very demanding because everyone has their own set of ideas and values that they feel are important. Another big issue that comes to my mind is time. Currently, I am the president of the Organization of Students With Disabilities (OSD) at SFSU. I also serve as a member of the search committee to find a new director for the disability services program on campus. I try to prioritize things according to their importance.

Another tactic for dealing with time demands is delegating power to other leaders or people who are in the development stage of leadership. I think that there is a common misconception in society of leaders being Ms. or Mr. Know It All. This is not true. Knowing who in the community to approach for specialized knowledge is a key aspect of leadership, and one which is required in order to manage one's time in the best way.

Getting involved in disability issues transformed me from one of the few shy mainstreamed kids in my school district to my leadership role on SFSU campus. In the future, I'd like to take a leadership role of advocating involvement in the local community on disability issues. I'd also like to work on advocating the independent living movement philosophy in the U.S. and other countries.

Ivana Kirola, a sophomore at San Francisco State University, is a 1994 Project LEEDS participant and attended the first National Institute on Disability and Leadership.

Remembering with Dignity: Leadership Through Activism

by Jerry Smith

Behind the old brick dormitory buildings of the regional treatment center in Faribault, Minnesota, stands a tall, white cross. Before the cross, just below ground level, lay flat steel plates stamped with a number. Laid in a grid, the hundreds of markers correspond to a chart, stored somewhere in the archives of the institution, of the people buried here over the past 120 years. Not unique to Faribault, tens of thousands of people who lived and died in our nation's institutions were buried anonymously. Kept hidden from society, these citizens were denied one last act of dignity: to have their names on their gravemarkers.

> ...tens of thousands of people who lived and died in our nation's institutions were buried anonymously. Kept hidden from society, these citizens were denied one last act of dignity: to have their names on their gravemarkers.

In September of 1994, members of the self-advocacy organization Advocating Change Together (ACT), along with members of the Minnesota Association of Persons with Severe Handicaps (MNASH), local People First chapters, the Minnesota Disability Law Center, and the community at large met to discuss the issue of placing markers on the graves on the many individuals with disabilities who lived and died in our state's regional treatment centers. As a matter of respect for institution residents, and for the dignity of those who have been fortunate enough to move out into the community, the group began a project called Remembering With Dignity to publicly recognize our forgotten citizens in state institutions and allow a healing process to begin for family and friends. With the planned closing of Minnesota's regional treatment centers within this decade, the group felt that a respectful acknowledgment of those who lived within our institutions would serve as a closure to our history of institutionalizing persons with developmental disabilities, and as a poignant reminder of how easy it is to separate ourselves from those we see as different.

Since the first meeting of Remembering With Dignity, participants – particularly those who have lived in institutions – have been passionate about the need for respectful gravemarkers at Minnesota's institutions. "My husband, Dean, lived in four institutions," said Gloria Steinbring, "Owatonna, Cambridge, Fergus Falls, and Faribault. When he died, I made sure he wasn't buried at the institution. His gravesite has his name on it, with the year he was born and the year he died. I'll be buried next to him." Many other participants in this group, including individuals who live in group homes and high-rises, and younger self-advocates who have never seen the inside of a regional treatment center, identify with this issue because they understand this injustice. "Many of us have been treated like a number all our lives by social workers," said Heidi Mhyre, a young self-advocate. "To be buried as a number isn't right; they should at least be given their name back."

Unlike many programs aimed at developing the individual leadership skills of persons with disabilities, Remembering With Dignity is developing leadership through grassroots organizing around an issue of common concern; people are drawn to participate through a feeling of injustice, and many assume leadership roles because they are acutely aware that no one knows better than they what it means to live in an institution. Some of the people involved in this group are active in their self-advocacy groups; others have never spoken out publicly. As advisors to Remembering With Dignity, members of ACT and MNASH have worked with the larger group in defining goals and strategies. Members of the group decided that their primary goal would be to place names and dates on the gravesites, beginning with one institution. As the Faribault regional treatment center is very quickly being converted to a corrections facility, the group decided to begin there, working with the local community to preserve the history of the institution as told by those who lived there. "This is our history," said Gloria Steinbring. "It belongs to us. We need to preserve it so people will know how we've lived and what we've been through."

While Remembering With Dignity has the support of advisors and professionals, its work and direction have been the responsibility of self-advocates. They have formed working groups, dividing the project into three areas: placing names on the gravesites, collecting oral histories of life in institutions, and increasing public awareness of the historical role of institutions for people with disabilities. As a first step toward placing names on the gravesites at Faribault, participants with an interest in community organizing have set the goal of identifying the names and dates of birth and death of the persons buried at the site. Having identified a committed group of self-advocates and community members in Faribault, the Twin Cities group will work with them to recruit volunteer support and also identify potential opposition to this project. At this stage, they have encountered no opposition; administrators at Faribault have been cooperative, expressing interest in having their history preserved. Community groups, including the Jaycees, have offered their assistance in raising funds for the markers.

The process of collecting oral histories is providing opportunities for individuals to share their stories with others who have lived in institutions, while developing presentation skills through conducting interviews. Upon collecting the oral histories, this group will explore ways to use these stories in a lasting public exhibit on lives lived in institutions. Cliff Poetz, of People First Central in Minneapolis, met with the Minnesota Historical Society to explore using oral histories as part of an exhibit on institutions. Group members – many of whom do not consider themselves leaders – are able to draw from their unique experiences with institutions and use them as a catalyst for recruiting new interviewees. Uncovering the stories of those who have lived in institutions is an act of historical and social significance; helping former institution residents understand their history and share in this process of healing is an act of leadership.

To increase public awareness of the past and present roles of institutions, group members are developing strategies for working with local media in communicating the goals of Remembering With Dignity and telling the first-person stories of life in institutions. The first task the public awareness working group accomplished was writing a one-line mission statement: "Honoring those who lived and died in Minnesota's state institutions by telling their stories and preserving our history." Self-advocates Barb Eaton, John Daggy, and Gloria Steinbring were chosen to serve as public speakers and contacts for the media. John, in his mid-60s, had never heard of self-advocacy before this issue. After learning of the effort to honor those who lived in institutions, John came forward and told his story of being committed to Faribault as a child. Over the past months he has visited the county courthouse repeatedly, looking for information on people he knew while at Faribault. Members of the group who are not as comfortable speaking publicly are working with volunteers in assembling a media kit containing photos of the cemeteries, a mission statement, the project goals, and information on how people can join this process. This group is also videotaping the organizing process, and will use this footage along with the oral histories to create a documentary program for public viewing.

Remembering With Dignity is developing leadership through grassroots organizing... many [people] assume leadership roles because they are acutely aware that no one knows better than they what it means to live in an institution.

Remembering with Dignity is also keeping a high-profile among legislators and other disability and social change organizations. Minnesota State Senator Linda Berglin, a strong supporter of disability rights, has asked the group to help write a resolution asking the State of Minnesota to formally apologize for institutionalizing persons with developmental disabilities. Steve Burnley, a man who lived in Cambridge state hospital from age 11 to 18, looked back on his years in the institution: "You know, no one ever said to me 'I'm sorry.' No one ever apologized for locking me up. I'd just like someone to apologize."

The Remembering with Dignity project is one of several similar efforts that have taken place across the country in recent years. Pennsylvania's former First Lady, Ginny Thornburgh, led an initiative to memorialize persons buried in Pennsylvania's state operated institutions for persons with mental retardation and mental illness by rededicating the cemeteries, placing new headstones on the graves bearing the deceased person's name and dates of birth and death. More recently, David Leshtz and Barbara Smith at the University of Iowa developed a program to record and tell the stories of people who lived in Iowa's institutions. Leshtz and Smith recruited members from the community – students, teachers, social workers, amateur historians, family members and friends – to interview former residents of Glenwood State Hospital School and Woodward State Hospital School. University of Iowa theatre graduate Todd Ristau used the oral histories to create the play, *Immigrants From Within*.

There are still 70,000 people with developmental disabilities living in public institutions, thousands more in private institutions, and hundreds who are admitted every year. The stigma of being labeled "mentally retarded" and removed from mainstream society has been felt by many Remembering With Dignity participants. The insult of thousands of anonymous gravesites is an enduring metaphor for our perceptions of disability. With the initiative and effort of leaders with disabilities such as those involved with Remembering with Dignity, people who lived and died in institutions are being remembered, and those who have survived the institutions are being given the opportunity to tell their stories, ensuring that this part of our history is not forgotten.

Jerry Smith is Communications Director with Advocating Change Together in St. Paul, Minnesota. For more information on Remembering with Dignity contact Walter Rupp at (612) 641-0297.

Resources

The following resources are related to the development of skills, attitudes, and opportunities necessary to support the leadership potential of individuals with developmental disabilities. Please contact the distributors listed for information about ordering the materials and for costs.

• **Self-Determination for Youth with Disabilities: A Family Education Curriculum** (1994). A 15-module curriculum developed to teach families skills for supporting the exercise of self-determination by their transition-age member with a disability. It is designed to be presented by teachers, community agency personnel, or other facilitators in a series of two-hour sessions. Available from the Publications Office, Institute on Community Integration, University of Minnesota, 109 Pattee Hall, 150 Pillsbury Dr. SE, Minneapolis, MN 55455 • (612) 624-4512.

• **Leadership for Empowerment Program: Serving Junior High Youth With and Without Developmental Disabilities** (1994). A curriculum that provides the tools for a youth development professional to begin an inclusive service leadership group or make an existing group inclusive. The manual addresses group formation, meaningful service, and reflection. Includes a videotape, program manual, posters, and resource brochures. Available from Polly Harrison, Ridgedale YMCA, 12301 Ridgedale Dr., Minnetonka, MN 55305 • (612) 544-7708.

• **Not Another Board Meeting: Guides to Building Inclusive Decision-Making Groups**. Three guides that raise questions about the supports group members need to make decision-making more meaningful for all. This tool brings self-advocates, support persons, and group members together to talk about their group's purpose. Available from the Oregon Developmental Disabilities Council, 540 25th Place NE, Salem, OR 97301 • (503) 945-9941.

• **People First: Leadership Training Manual (1988).** A manual written to help self-advocates learn to organize and to stand-up for their rights. It defines self-advocacy and leadership; describes how People First and other groups can help self-advocates; and talks about organizing, strengthening, and advertising a group, and choosing an advisor. Available from National People First Project, Kinsmen Building, 4700 Keele St., Downsview, Ontario M3J 1P3 Canada • (416) 661-9611.

• **Taking Charge** (1993). A leadership training project designed for groups of 10-12 people, about 14 hours in length. It combines personal development exercises with skill building in small and large group process, speaking, writing, planning, and goal setting. Available from Heritage Centers of Buffalo, 101 Oak St., Buffalo, NY 14203 • (716) 856-4201.

• **Voices That Count: Making It Happen (1993).** A presenter's guide written to help self-advocates learn the skills necessary to speak to groups about leadership roles and opportunities. Speakers using the guide will give boards and committees ideas on how they might recruit and build partnerships with self-advocates. There is an audiotape of the guide to assist users, and there is also a videotape to be used as part of the presentation to boards. Available from Cincinnati Center for Developmental Disorders (UAP), 3300 Elland Ave., Cincinnati, OH 45229 • (513) 559-4639 / 559-4626 (TDD).

• **No More B.S.: A Realistic Survival Guide for Disability Rights Activists** (1992). A book addressing self-advocacy as part of the broader disability rights movement. It provides information, resources, and motivation about organizing to make change in the lives of people with disabilities. Available from People First of Washington, P.O. Box 648, Clarkston, WA 99403 • (509) 758-1123.

• **Spreading the Word** (1993). A booklet on self-advocacy based on what Speaking for Ourselves has learned over the past 10 years. It is written for members of self-advocacy groups to use together. Topics covered include where the group started, who the members are, principles for which the group stands, how the group is organized, definition of a chapter, what happens in the chapter, how members are involved, and the advisor's role. Available from Speaking for Ourselves, One Plymouth Meeting, Suite 530, Plymouth Meeting, PA 19462 • (610) 825-4592.

• **A Call to Action: The Roles of People with Mental Retardation in Leadership** (1992). A handbook outlining the proceedings from the leadership forum held during the Arc's 1991 national convention. It also discusses barriers and strategies to supporting leadership of people with mental retardation. Available from Arc National Headquarters, P.O. Box 1047, Arlington, TX 76010 • (817) 261-6003.

• **Self-Advocacy: Print and Media Resources** (1995). A guidebook listing nearly 150 publications and media materials about self-advocacy. Topics include building self-advocacy groups, financial issues, health and medical concerns, legal rights, self-advocacy skills, the Americans with Disabilities Act, and Personal Futures Planning. Available from Institute on Community Integration, University of Minnesota, 109 Pattee Hall, 150 Pillsbury Dr. SE, Minneapolis, MN 55455 • (612) 624-4512.

Eaton, continued from page 1

called Remembering with Dignity (see story on page 24). "I got involved with Remembering with Dignity because I've been there. I told my own story and now I want to help others do the same. I'd want someone to do this for me."

Barb brings her experience and a great deal of sensitivity to the organizing sessions for Remembering with Dignity. Her leadership ability shows through in her comments and suggestions about the importance of preserving and telling the life stories of people with disabilities. She understands the importance of people with disabilities themselves owning and taking on the responsibility to document their history. In a recent organizing session, Barb worked in a small group to create a statement that describes the Remembering with Dignity mission: "Honoring those who have lived and died in Minnesota's state institutions by telling their stories and preserving our history." Barb says that she is proud of this statement and that she feels that her own experiences were helpful in writing it.

Barb Eaton didn't learn to be a leader by participating in a program or project to develop such skills. Her leadership skills were developed by doing. She was motivated by an issue and the desire to make change in her own life and the lives of others. "I think a leader is someone that knows what they want and they have goals and they just do it. Leaders have gumption." She says that she will continue to work on issues of concern to people with disabilities long into the future and that such work is her job. This quote from T.S. Eliot, which opens the video documentary about Barb, expresses her belief that often the effort is as important, if not more so, than the outcome: "There is only the fight to recover what has been lost. And found, and lost again... But perhaps neither gain nor loss, for us there is only the trying." Barb agrees. "I will work with groups like the Remembering with Dignity group or all alone. It depends. If something needs to be done to help people or make things better, I'll work to do it. I just want to get things done."

Walter Rupp is the Community Organizer for the St. Paul, Minnesota, self-advocacy group, Advocating Change Together, which is the home of Remembering with Dignity.

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themselves as leaders, it is likely that most will live their lives without ever reaching their potential to contribute to the community in a leadership role. If current trends continue and persons with disabilities are not provided with opportunities to acquire, practice, and refine those capacities that will allow them to effectively function within leadership positions, a void will be created that may take years to fill. The lack of opportunity within this area has already created a situation in which many creative, highly skilled individuals are never able to use their talents to improve the quality of their own lives as well as those of others.

What can be done to facilitate persons with disabilities filling leadership roles? To train the leaders of tomorrow, leadership instruction must be provided, not only to adults, but to children and youth as well. Along with opportunities to acquire basic skills within this area, persons with disabilities must also be given the chance to serve in leadership capacities within society at large. Efforts must also be made to insure that color, gender, economic background, and the presence of a disability do not preclude an individual's functioning in a leadership role. For all persons, leadership development starts with full participation in school, work, and community life and the development of a sense of self-determination. It culminates as individuals move themselves and subsequently others from dependence to interdependence, from being spectators to leaders.

Brian Abery is Coordinator of School Age Services and Michael N. Sharpe is a project coordinator, both with the Institute on Community Integration, University of Minnesota, Minneapolis. Brian may be reached at (612) 625-5592 and Mike at (612) 624-0096.

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workshop in April of 1994. As a member of this year's futures planning committee, she shared her insights on how the workshops could be improved and the parts that should remain the same. The CTIC had become involved in a grant to pilot a new IEP form, the Minnesota Individual Family Plan of Interagency Support, and the futures planning committee spearheaded the implementation of this new project. The new committee's goal was to get at least 10 plans written in Goodhue County by June of 1995. It was decided to conduct an inservice training on the new plan for teams interested in the concept of one interagency service plan for students with disabilities and their families. Jenny and her family volunteered for the starring roles in the videotape prepared for the inservice training.

At each monthly meeting, I watched the three students become more and more confident in giving their input. They have become truly valued members of the GCED - CTIC, so valuable, in fact, that we have asked them to return next year. They all agreed to continue their roles on the CTIC, even Jenny, who will graduate in June. We hope that they will become the mentors for future student leaders.

Julie Schreifels is a member of the GCED-CTIC, and a teacher at Red Wing Central High School, Red Wing, Minnesota. For more information on student involvement in Community Transition Interagency Committees, contact Julie at (612) 388-7181.

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IMPACT: Feature Issue on Leadership • Summer 1995

Managing Editor: Vicki Gaylord
Issue Editors: Brian Abery, Jerry Smith, Michael N. Sharpe, and Gene Chelberg

IMPACT is published quarterly by the Institute on Community Integration (University Affiliated Program), and the Research and Training Center on Residential Services and Community Living, College of Education and Human Development, University of Minnesota. This issue was supported, in part, by Grant #90DD032301 from the Administration on Developmental Disabilities, U.S. Department of Health and Human Services; by Grant #H133B30072 from the National Institute on Disability and Rehabilitation Research, U.S. Department of Education; and by Grant #HO23C20033 from the Office of Special Education Programs, U.S. Department of Education. The opinions expressed are those of the authors and do not necessarily reflect the views of the Institute, Center, University of Minnesota, or their funding sources. The missions of the Institute and Center are to improve the quality and community orientation of professional services and social supports available to individuals with disabilities and their families. Inquiries about *IMPACT* can be directed to:

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